Challenges in Viral Hepatitis: Community Perspectives

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China Viral Hepatitis Needs Assessment - Background

- Funded through Coalition to Eradicate Viral Hepatitis in Asia Pacific (CEVHAP)
- Chief Investigators
  - ARCSHS – Jack Wallace, Prof Marian Pitts, Behzad Hajarizadeh, Jacqui Richmond,
  - La Trobe China Health Program – Prof Vivien Lin and Chaojie (George) Liu
  - Prof Wei Lai, Peking University People's Hospital
  - Prof Stephen Locarnini, Doherty Institute
China Chronic Viral Hepatitis Needs Assessment - Methods

• Document the personal impact of infection with viral hepatitis, and identify the issues arising for people in responding to the infection

• Two processes
  • Interviews with key stakeholders (13)
  • Interviews with people with hepatitis B (41) or hepatitis C (5)
## China Chronic Viral Hepatitis Needs Assessment - Methods

<table>
<thead>
<tr>
<th>Age range</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-25 years</td>
<td>9</td>
</tr>
<tr>
<td>25-30 years</td>
<td>13</td>
</tr>
<tr>
<td>30-35 years</td>
<td>10</td>
</tr>
<tr>
<td>35-40 years</td>
<td>4</td>
</tr>
<tr>
<td>40-45 years</td>
<td>2</td>
</tr>
<tr>
<td>45-50 years</td>
<td>3</td>
</tr>
<tr>
<td>50-55 years</td>
<td>2</td>
</tr>
<tr>
<td>55-60 years</td>
<td>2</td>
</tr>
<tr>
<td>Over 60 years</td>
<td>1</td>
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</tbody>
</table>
## China Chronic Viral Hepatitis Needs Assessment - Methods

<table>
<thead>
<tr>
<th>Location</th>
<th>Number of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beijing</td>
<td>17</td>
</tr>
<tr>
<td>Guangzhou</td>
<td>15</td>
</tr>
<tr>
<td>Shanghai</td>
<td>11</td>
</tr>
<tr>
<td>Dong Guan</td>
<td>2</td>
</tr>
<tr>
<td>Chongqing</td>
<td>1</td>
</tr>
</tbody>
</table>
China Chronic Viral Hepatitis Needs Assessment - Findings

1. Testing
2. Being diagnosed
3. Information
4. Treatment
5. Psychological impact
6. Social impact
China Chronic Viral Hepatitis Needs Assessment - Testing

• **School** - I was 6 years old .... every student was asked to do the body check, and at that time I got to know that I was carrying the hepatitis B virus (Female, 30-35yo, hepatitis B, Guangzhou10).

• **University** - During the university entrance health-check, my teacher handed me a report and asked me to have a further virus count test for hepatitis B. That was when I knew that I was a hepatitis B carrier (Female, 20-25yo, hepatitis B Shanghai20).
China Chronic Viral Hepatitis Needs Assessment - Testing

- **Workplace** - *I had been working for a company for half a year when the company conducted a welfare health-check, that’s when I found out that I had hepatitis B.* (Male, 25-30yo, hepatitis B, Beijing42).

- **Hospital** – *At first it was my daughter who got sick with hepatitis B, and … the professor (at the hospital) told me: “Your daughter has hepatitis B, it’s better for the parents to have a check-up as well.” … So both me and my wife had a check-up … and were diagnosed with hepatitis B. I had hepatitis B E-positive, my wife had E-negative, my daughter was also E-positive.* (Male, 35-40yo, hepatitis B, Guangzhou 7).
## China Chronic Viral Hepatitis Needs Assessment – Being Diagnosed

<table>
<thead>
<tr>
<th>Informed of infection by:</th>
<th>Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood donation</td>
<td>3</td>
</tr>
<tr>
<td>High School</td>
<td>4</td>
</tr>
<tr>
<td>Hospital</td>
<td>12</td>
</tr>
<tr>
<td>Junior high school</td>
<td>5</td>
</tr>
<tr>
<td>Medical check-up</td>
<td>4</td>
</tr>
<tr>
<td>Parents</td>
<td>7</td>
</tr>
<tr>
<td>Primary school</td>
<td>3</td>
</tr>
<tr>
<td>University</td>
<td>6</td>
</tr>
<tr>
<td>Workplace</td>
<td>2</td>
</tr>
</tbody>
</table>
China Chronic Viral Hepatitis Needs Assessment – Being informed

• **Parents** - I was still a little child; my mother didn’t tell me bluntly what I had, she just … told me not to do intense exercise, even though I did like running and other sports a lot (Female, 20-25yo, hepatitis B, Shanghai27)

• **Health staff** - He (the doctor) just told me: “You have hep B.” and that’s it. I didn’t know what risks this disease would have on my health (Female, 30-35yo, hepatitis B Guangzhou2).
China Chronic Viral Hepatitis Needs Assessment – Being informed

- **Teachers** - *There was (a test) before going to high school, during which I was found to be a hepatitis B carrier… the teacher posted the health check results on the classroom wall … so individual students could go and check what sort of problems they had, for example, short-sightedness* (Female, 25-30yo, hepatitis B, Shanghai27).
(The doctor) just gave me a report saying I was a hep B carrier. E-negative, and that’s it …. He just told me: “You have hep B.” and that’s it. I didn’t know what risks this disease would have on my health (Female, 30-35yo, hepatitis B Guangzhou2).

She told me that my surface antigen was positive, but the rest of the result such as liver function and HBV level were normal. I didn’t know much about it, all I knew was it’s a scary disease (Male, 30-35yo, hepatitis B, Beijing46).
China Chronic Viral Hepatitis Needs Assessment – Economic Impact

• It placed a huge financial pressure on me as my whole family had the same disease, the pressure was unbearable … my wife has to take medication, I have to take medication, my daughter has to take medication (Male, 35-40yo, hepatitis B, Guangzhou7).

• If I have money, I can receive the best treatment … my parents are frustrated right now, and they want me to stop taking medication, but I don’t dare to … they suffer because of me (Male, 20-25yo, hepatitis B, Guangzhou12).
China Chronic Viral Hepatitis Needs Assessment – Treatment

• I didn’t receive treatment right away because I didn’t have enough money (Male, 35-40yo, hepatitis B, Guangzhou 4).

• I need to think about my financial situation when I make decisions. I need to compare the price… I need to find out whether expensive medication is more effective than cheaper ones. I need to take all these into consideration (Male, 30-35yo, hepatitis B, Beijing 46)

• I found a senior professor … I told him my family’s financial situation’s not very good, so he recommended me to have Lamivudine (Male, 35-40yo, hepatitis B, Guangzhou4).
China Chronic Viral Hepatitis Needs Assessment – Disclosure

- I’m in a dilemma. One way you want people to accept you, and under the condition that they know that you have this disease, but on the other side I am afraid to tell them because I am afraid I will be rejected. (Female, 20-25yo, hepatitis B, Beijing40).

- They don’t know I have it. My parents had tests done and found out that they too had hepatitis … I don’t want them to worry about me because my family was very worried when they found out about my brother’s disease (Male, 25-30yo, hepatitis B, Beijing42).
China Chronic Viral Hepatitis Needs Assessment – Discrimination

- The public are generally still ignorant about the disease, they think it is easily transmitted, it is a serious disease. (Female, 25-30yo, hepatitis B, Chongqing28).

- There’s no vaccination to discrimination … it is always there. There is no way you can tell a granny at the age of 80 that you shouldn’t discriminate (against) people with the hep B, it all starts from a very young age … and there’s no way you can turn things around (Male, 30-35yo, hepatitis B, Guangzhou1).
Conclusions – World Health Organisation Axis

1. **Raising awareness, promoting partnerships and mobilising resources**
   - Authoritative information campaigns targeting general public, health care workers and people with viral hepatitis.
   - National roundtable of key stakeholders for a national action plan
   - Education of all health care workers

2. **Evidence-based policy and data for action**
   - Identify priorities for epidemiological, clinical, public health and social research and conduct economic analysis of not treating.
   - National plan to reduce the burden of viral hepatitis and that acknowledges and addresses the social implications of hepatitis infection
   - Investigate the enablers and barriers to clinical management services,
Conclusions – World Health Organisation Axis

3. Prevention of transmission
   • Continue to monitor and report on the national hepatitis B vaccination program, addressing gaps when evident
   • Continue to develop and implement infection control processes.
   • Conduct professional development of all health care workers about viral hepatitis, including transmission routes.

4. Screening, care and treatment
   • National viral hepatitis testing/diagnosis policy
   • Address barriers to poor clinical monitoring rates
   • Ensure treatment choices are determined by clinical rather than economic issues
   • Develop treatment guidelines address issues related to the use of TCM
Thank you

- People with viral hepatitis
- Vicki Ang for her organisational and linguistic skills.
- Key thanks to the Inno Community Development Project (Guangzhou), Lei Chuang and Professors Hou and Jia.
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