Hepatitis C as a systemic disease: The patient’s point of view

Charles Gore
Hepatitis C as a systemic disease

PATIENTS’ PERCEPTION

• The experience of hepatitis C is very individual

• For those with significant symptoms it can feel very much like a systemic disease

• With physical, emotional and psychological symptoms

• And even more than that, it can impact all areas of a person’s life
Hepatitis C is a systemic disease

IMPLICATIONS FOR PATIENTS

• An explanation of symptoms
• Does this change what is meant by severity of disease?
• What does this mean for treatment prioritisation?
• What precisely is cured by successful anti-viral treatment?
• What is the impact on life expectancy, insurance etc?
“Chronic hepatitis C is usually asymptomatic”

- Is this true?

- Lack of symptoms often cited as an explanation of low diagnosis rates

- Often vague and inconsistent symptom profile:
  - cognitive dysfunction
  - depression
  - fatigue
  - aches and pains (liver area/joints)
  - digestive problems
  - skin issues
  - sexual dysfunction

- Ability to imperceptibly adjust over time

- Symptoms more noticeable retrospectively (in those cured)
Severely of disease

- Severity is still linked to liver damage and inflammation
- One reason symptoms have been downplayed is that they do not correlate with liver damage
- Yet the severity of symptoms is what impacts a patient's life:
  - Ability to work
  - Financial situation
  - Social life
  - Relationships
  - Feeling of well-being/mental health
- What is the impact of symptoms on the psychology of substance use?
- What is the impact of systemic issues on comorbidities?

This is hepatitis...
Stigma and discrimination

- Neuropsychoimmunology and the relevance of stigma and discrimination to the ‘system’
- Stigma may preventing diagnosis (and hence treatment)
- Stigma and discrimination may prevent access to care and support that could address non liver-related issues
- Stigma and discrimination may prevent PWID getting HCV treatment and then addressing other issues
Implications for prioritisation

- Are all genotypes as likely to cause systemic issues?

- What factors (e.g. age, length of infection, fibrosis, inflammation, immune response, genetics) are predictors of the worst non liver-related outcomes?

- When to treat for the biggest return in terms of non liver-related outcomes (does it matter?)?
And after cure?

- Not all patients are well after cure
- What is happening to the immune system (cure is possible even when the drugs are stopped with measurable viral load)?
- Which risks remain?
- What should be monitored?
- What are the financial implications for patients?
- What would be a systemic approach to curing someone?
Hepatitis C as a systemic disease

• Importance of considering the totality of having hepatitis C and its impact

• Importance of seeing the totality of a person, not just a pathogen
THANK YOU