

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

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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)

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Severity 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 patients' 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?

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Stigma and discrimination

- Neuropsychimmunology 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

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THANK YOU

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