In HCV-Infected Patients, Internalized Stigma and Experienced Stigma are Correlated with Psychological State and Health-Related Quality of Life: Baseline Data from the PROP UP Study

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Background

- People with hepatitis C encounter stigma due to their status1-3
  - Experienced or “enacted” stigma (effect on identity and self-esteem)
  - Hepatitis C-related stigma is associated with4
    - Anxiety
    - Depression
    - Cognitive problems
    - Worse symptoms
    - Less acceptance of illness
  - Stigma causes barriers to care5

  PROP UP: a chance to study hepatitis C stigma
  - Study of how patient-reported outcomes (PROs) change in the real world over course of HCV treatment6
  - SSCI-8 (a validated stigma measure)7 added to PROP UP battery
  - Overall Research Question:
    In an era of straightforward HVC cure, what are the correlates of stigma at pre-treatment baseline?

Methods

**Stigma Scale: SSCI-8 (NeuroQOL-Stigma)**

- Items made with a two-factor structure
  - 2 items related to internalized stigma (e.g., HCV has shaped identity)
  - 4 items related to experienced stigma (e.g., HCV stigmatizes people)
- Items contribute to an experienced stigma factor (hurt)
- 6 items contribute to an experienced stigma factor (stress)
- Several people asked to tiem to the questions
- Some people asked to tiem to the questions
- Because of my HCV, I fell ill of things
- Because of my HCV, some people treated me differently
- Because of my HCV, people were less kind to me
- Because of my HCV, people seemed uncomfortable talking to me

**Variables from PROP UP Data Set**

- Demographic factors (DIY)
  - Age
  - Sex
  - Race
  - Education
  - Household Income
  - Birth Sex
  - Employment
  - Number of people in household
- Patient report outcomes (PROs)
  - Fatigue
  - Depression
  - Anxiety
  - Sleep
  - Employment
  - Work Ability
  - Pain
  - Fatigue
  - DEB
  - Anxiety
  - Anger
  - Depression

**Participant Flow Diagram**

1602 participants in PROP UP

1263 with at least partial baseline SSCI-8

26 with incomplete baseline SSCI-8

Significant Stigma: SSCI-8 > 1.5

Significant Experienced Stigma: SSCI-8 > 1.5

**Outcome Measures**

- Fatigue
- Depression
- Anxiety
- Sleep
- Employment
- Pain
- Work Ability
- Pain

**Baseline Data from the PROP UP Study**

**Overall Stigma Baseline Prevalence**

<table>
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<th>Event</th>
<th>Small (n = 100)</th>
<th>Medium (n = 300)</th>
<th>Large (n = 1000)</th>
<th>Significance (p value)</th>
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<td>Medium</td>
<td>Large</td>
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</tr>
<tr>
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<td>0.934</td>
<td>0.975</td>
<td>&lt;0.001</td>
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</tr>
</tbody>
</table>

**Statistical Analyses**

- Response frequency binomial of individual items
- Prevalence of any stigma (at least one Rarely or Higher) on Fatigue and Depression
- Prevalence of significant stigma (at least one Sometimes or Higher) on Fatigue and Depression
- Multinomial regression analyses of ORs associated with Fatigue and Depression
- Logistic regression analysis, adjusting for ORs, of association of Fatigue and Depression with mental/social PROMIS Short Form scales and with HCV-PRO quality of life scale

**Results**

- The prevalence of clinically significant stigma was 41.7% for internalized and 25.8% for experienced stigma
- Internalized stigma was significantly associated with lower rates of both internalized and experienced stigma
- The interaction term did not further significantly improve the model, i.e., an additive effects between the two types of stigma.

**Conclusions**

- Black race, older age, and being employed were associated with lower rates of both internalized and experienced stigma.
- Both internalized and experienced stigma were associated with increased intensity of all 5 somatic/psychological patient-reported outcomes, and decreased quality of life, with additive effects between the two types of stigma.

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**References**