## Reasons New York City Patients are Not Prescribed Hepatitis C Treatment

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ON HCV AND HIV DIAGNOSIS, PREVENTION AND ACCESS TO CARE

#### **OBJECTIVES**

- To describe clinical and social factors related to treatment initiation among New York City residents with chronic hepatitis C virus (HCV) most likely to be considering HCV treatment.
- To assess reasons these patients may not receive antiviral treatment.

#### BACKGROUND

HCV is the most common blood-borne infection in the United States, affecting over 3 million people [1, 2], of whom an estimated 146,000 live in New York City (NYC) [3].

Recent developments in HCV treatment have yielded all-oral interferon-free medications with cure rates over 90%. These treatments have almost no contraindications, are simpler to take and have fewer and less severe side effects than interferon-based regimens, however, they are very expensive, costing over \$80,000 for a course of treatment [4].

Even with these advances, many patients face barriers to initiating HCV treatment, including lack of insurance, high insurance co-pays, insufficient liver disease progression to qualify for treatment according to health insurance policies, lack of awareness of programs that cover cost of care for uninsured or under-insured, difficulty accessing specialists, and concern about side effects [5-7]. We conducted a survey to explore reasons NYC patients are not being prescribed HCV treatment, from both a patient and provider perspective.

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#### **METHODS**

The authors selected persons most likely to have been treated from the New York City Health Department's routine hepatitis C surveillance database. We included persons ages 31 to 70 with a positive HCV RNA result at least one year earlier, any HCV result since June 2012, and no known negative RNA result. From the resulting 31,179 adults we randomly sampled 300 persons. We collected information on demographics, treatment, and barriers to treatment from both providers and patients by telephone, fax, mail, or medical record review.

#### RESULTS

Of 300 patients sampled in June 2014, exclusion criteria eliminated 91 patients: 7 resided outside NYC, 13 were deceased, 10 patients/providers were unable to be reached, 13 had a most recent RNA negative result, 24 were currently on treatment, 10 recently finished treatment, 14 were cured. The remaining 209 (70%) patients known to be HCV-infected at the time of the study are the focus of this analysis. We collected data from providers for all 209 patients, and interviewed 88 (42%) of the patients. Clinician questionnaires were completed by phone (43%), chart review (30%) and fax (27%). Patient data was obtained by phone (88%) or mail (12%).

Figure 1: Sampling and inclusion in analysis dataset

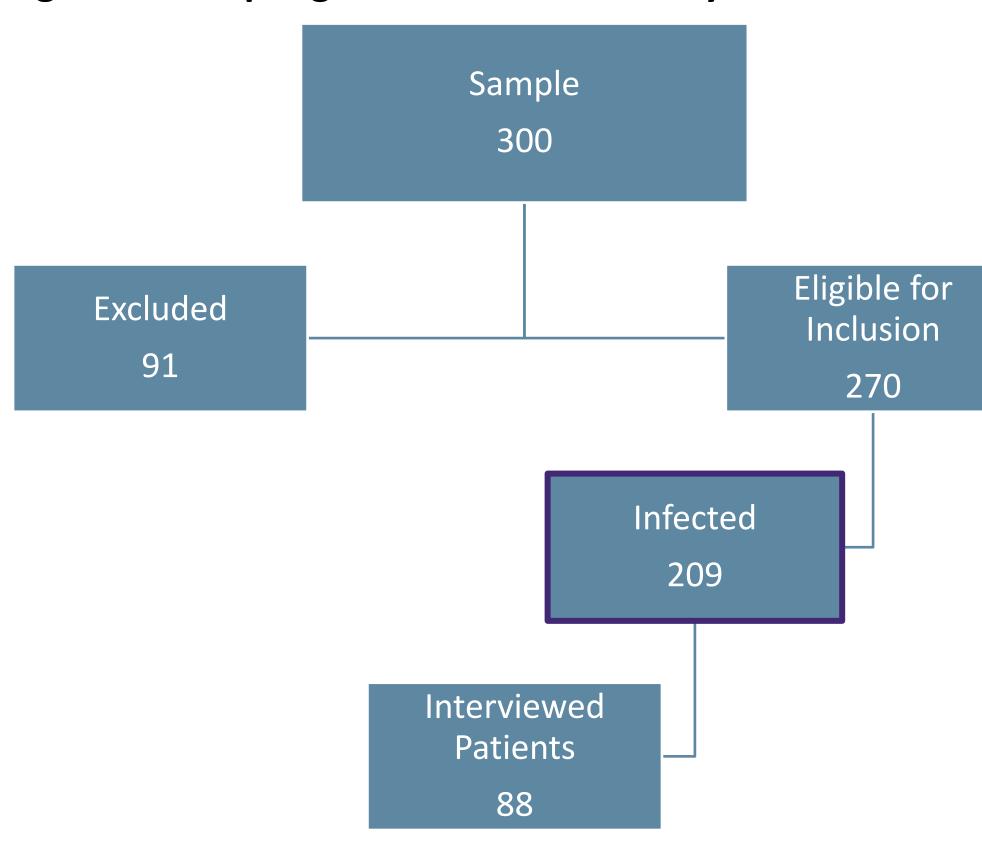


Table 1: Characteristics of Individuals in the **Analysis Dataset** 

Allarysis Dataset		
	N	%
Total	209	100%
Sex		
Male	139	67%
Female	70	33%
Age		
Birth Cohort (1945 - 1965)	163	78%
Other	46	22%
Insurance		
Medicaid	117	56%
Private	51	24%
Medicare	14	7%
Other	2	1%
None	6	3%
Unknown / Unspecified	19	9%
Provider Discussed HCV Treatment witl	h Patient	
Yes	154	74%
No	46	22%
Unknown	9	4%
Genotype		
1a or 1b	157	75%
3 or 3a	14	7%
2a or 2b	6	3%
Other	4	2%
Unknown	28	13%
Other	4	2%

Table 2: Barriers<sup>1</sup> experienced by NYC patients who are most likely to be on **HCV** treatment and are not prescribed HCV treatment

	Provider reports	Patient self- reports
Barrier to hepatitis C treatment	(179 patients)	(87 patients)
Comorbid condition	41%	34%
Currently drinks alcohol or uses drugs	24%	3%
Medical condition	21%	20%
Mental health issue	19%	13%
Not keeping follow-up or referral appointments <sup>2</sup>	28%	$NA^3$
Provider does not prescribe HCV medications, refers for treatment <sup>4</sup>	22%	NA <sup>3</sup>
Concern over side effects	14%	30%
Waiting for better treatment regimen	13%	17%
Concerns over cost or insurance problems	4%	14%
Too many responsibilities	NA <sup>5</sup>	8%
History of non-adherence to medications	8%	0%
Disease not advanced enough	6%	7%
"No barriers to treatment" <sup>2</sup>	6%	11%

- <sup>1</sup>This table summarizes barriers reported by >5% of patients or providers. Categories are not mutually exclusive. <sup>2</sup> Received as a write-in response and standardized for inclusion in this table. All other responses were selected from a checklist.
- <sup>4</sup>72 of the 179 providers (40%) were primary care/internal medicine doctors. 62% of affirmative responses for this
- barrier were from primary care/internal medicine providers. <sup>5</sup>Not asked of providers

#### Table 3: Barriers to HCV Treatment as Described by Patients

"I don't want to be guinea pig for the new medication."

"I'm scared about the side effects of treatments. I got referred to Hospital X but missed the appointment because I had to pick my daughter up from school"

"My insurance denied my request to start treatment because my liver damage has not progressed far enough."

"I don't feel comfortable with my primary care provider. My doctor keeps on pushing me to get another liver biopsy and I don't want to do it. Also, he keeps pushing me to go to a GI specialist that I don't like."

"The pills are too expensive. My daughter has hep C too, and I don't think she will be covered. I don't want to get cured if she can't get cured too."

#### CONCLUSIONS

This investigation into reasons NYC patients have not been treated for HCV found a number of barriers to initiating treatment.

- Overall, a combined 41% of providers reported that patient alcohol, drug use or comorbid conditions were key reasons precluding treatment, identifying a gap in provider knowledge of current HCV treatment recommendations and contraindications and on the success of treatment in persons with co-morbid conditions.
- Providers commonly cited that patients often do not keep referrals to specialists and follow-up appointments, and are potentially lost to care.
- Nearly a quarter of providers surveyed said that that they do not treat HCV but rather refer patients to specialists for treatment.
- The most common barrier reported by patients was concern about HCV treatment side effects, cited by one-third of patients; this demonstrates the importance of increasing patient awareness about new treatments which have much milder side effects.

#### RECOMMENDATIONS

Because so many New Yorkers and their medical providers are identifying barriers to HCV treatment, it is important to find solutions and make resources available to overcome barriers.

- Improving the skills and treatment capacity of providers (especially primary care providers) who care for HCV-infected individuals will decrease the need for referrals and likely reduce loss to follow-up.
- Increasing attendance to medical specialist appointments and adherence to treatment can be achieved through a variety of linkage to care strategies such as telephone, text, online or in-person services, including referral to programs with patient navigation resources.
- Public health campaigns can provide information that new HCV medications are all oral, with shorter duration of treatment, and are more tolerable and more effective than older regimens.
- Providers can be informed that most drug, alcohol, mental health issues, and medical comorbidities are no longer clear contraindications to HCV treatment

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