Hepatitis C Surveillance among Youth and Young Adults in New York City, 2009–2013

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ABSTRACT *Increases in prescription opioid misuse, injection drug use, and hepatitis C infections have been reported among youth and young adults in the USA, particularly in rural and suburban areas. To better understand these trends in New York City and to characterize demographics and risk factors among a population who, by virtue of their age, are more likely to be recently infected with hepatitis C, we analyzed routine hepatitis C surveillance data from 2009 to 2013 and investigated a sample of persons 30 and younger newly reported with hepatitis C in 2013. Between 2009 and 2013, 4811 persons 30 and younger were newly reported to the New York City Department of Health and Mental Hygiene with hepatitis C. There were high rates of hepatitis C among persons 30 and younger in several neighborhoods that did not have high rates of hepatitis C among older people. Among 402 hepatitis C cases 30 and younger investigated in 2013, the largest proportion (44 %) were white, non-Hispanic, and the most commonly reported risk factor for hepatitis C was injection drug use, mostly heroin. Hepatitis C prevention and harm reduction efforts in NYC focused on young people should target these populations, and surveillance for hepatitis C among young people should be a priority in urban as well as rural and suburban settings.*

KEYWORDS *Hepatitis C, Surveillance, Youth, Young adults, Adolescents, Public health*

INTRODUCTION

Hepatitis C virus (HCV) is a major cause of chronic liver disease, with an estimated prevalence of HCV infection of 1.3 % in the USA¹ and 2.4 % in New York City (NYC).² The primary risk factor for HCV infection in the USA is injection drug use. It is estimated that up to 70 % of people who inject drugs are infected with HCV.³

Though the age group with the highest prevalence of HCV in the USA is the “baby boomers,” born between 1945 and 1965,⁴ there have been several reports in recent years of increases in infections among youth and young adults. Massachusetts,^{5,6} New York state,⁷ and Wisconsin⁸ have all reported increases and/or outbreaks of HCV among under-30-year-old injection drug users. A study of incarcerated 18–28-year olds in Rhode Island also showed a recent increase in HCV prevalence in this population.⁹ The increase in HCV infections among youth and young adults may be attributable to prescription opioid misuse and injection drug

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use, which has also been increasing in similar age groups.^{10–13} It has been demonstrated that some prescription opioid abusers transition to injection drug use,^{6,14–17} putting them at increased risk for acquiring blood-borne infections such as HCV and HIV.

Identifying new HCV infections is challenging. Since most people who are newly infected with HCV are asymptomatic, acute infection with HCV is rarely diagnosed and reported.¹⁸ Therefore, HCV diagnoses often occur years after initial infection, and new HCV diagnoses do not usually represent new HCV infections. By virtue of their age, young people newly diagnosed with HCV are more likely to have been recently infected than older people who are newly diagnosed but may have been living with chronic infection for decades. Thus, young age is a useful proxy for recent HCV infection, and understanding the epidemiologic and demographic characteristics of young people newly diagnosed with HCV can inform primary prevention policy by illustrating which populations should be targeted in prevention initiatives.

To better understand demographics and risk factors of youth and young adults with HCV in NYC, we analyzed routine HCV surveillance data, and we investigated a sample of persons 30 and younger newly reported with HCV.

METHODS

Surveillance Data

All positive HCV antibody tests with a high signal-to-cutoff ratio, HCV RNA tests, and HCV genotype tests among NYC residents, excluding rapid HCV tests, are routinely reported to the NYC Department of Health and Mental Hygiene (DOHMH).¹⁹ Over 95 % of reports of HCV are sent to DOHMH via electronic laboratory reporting. All individuals with a positive HCV test are counted as HCV cases, regardless of whether or not a confirmatory RNA test was done and reported to DOHMH. This is consistent with the CDC/CSTE case definition for hepatitis C, past or present,²⁰ and reflects the fact that many individuals who test positive for HCV antibody do not receive an RNA test to confirm their current infection status.^{21,22} Automated systems are used to match multiple reports for each patient.

All persons newly reported with HCV with diagnosis dates between 2009 and 2013 were included for analysis. We compared the sex distribution of cases across age groups using Pearson's chi-squared test. Cases were mapped by United Hospital Fund neighborhoods, which are aggregations of contiguous zip codes used to define communities.²³ Incarcerated individuals were excluded from the neighborhood analysis. Population data from the 2010 Census were used to calculate rates for each neighborhood; rates were averaged over the 5-year period of 2009–2013. Choropleth maps of HCV rates by neighborhood were created by age group; neighborhoods were stratified by quintile of HCV rate. The following age groups were used for analysis: <18-, 18–21-, 22–25-, 26–30-, 31–45-, 46–66-, and >66-year olds. The 46–66-year-old age group represents the baby boomer cohort in 2011, midway through the analysis time period. The main goal of the surveillance data analyses was to compare the youngest age groups (≤ 30 -year olds) with the baby boomer cohort (46–66-year olds).

For each neighborhood and for NYC overall, the relative rate of HCV in the ≤ 30 -year-old age group compared with the rate of HCV in the 46–66-year-old age group was calculated. The relative rate in each neighborhood was divided by the relative

rate in NYC to compute a relative rate ratio, and 95 % lower one-sided confidence bounds for this ratio were calculated. If the value of the lower confidence bound was greater than 1 for a particular neighborhood, this neighborhood was considered to have a significantly higher rate of HCV among ≤ 30 -year olds versus 46–66-year olds compared with NYC as a whole.

Reported addresses of persons newly reported with HCV between 2009 and 2013 were geocoded to 2010 census tract boundaries, and rates of HCV were calculated by census tract poverty level. Incarcerated individuals were excluded from the poverty analysis. Results from the 2008–2012 American Community Survey were used to determine the poverty level of each census tract (very low poverty, <5 % of residents have household incomes below 100 % of the federal poverty level; low poverty, 5 to <10 %; medium poverty, 10 to <20 %; high poverty, 20 to <30 %; very high poverty, 30 to <40 %; and highest poverty, ≥ 40 %). Census tracts in which there were no people for whom poverty status is determined (the Census Bureau does not determine poverty for those in group quarters, e.g., jails, nursing homes, and college dorms) were not assigned a poverty level. HCV rates for each census tract poverty level by age group were calculated using 2010 census population data and averaged over the 5-year period of 2009–2013. Chi-squared tests for trend were performed to assess whether trends in HCV rates by census tract poverty level were significant.

Case Investigations

DOHMH investigated all 0–21-year olds newly reported with HCV, and a random 50 % sample of 22–30-year olds newly reported with HCV. Cases selected for investigation with diagnosis dates from January 1, 2013, through December 31, 2013, were included for analysis. Information was collected from healthcare providers, by fax, phone, or review of the patient's medical chart, including patient demographics, reason for HCV testing, the provider's interpretation of the positive HCV result and estimate of when the patient was infected, and the patient's risk factors for HCV, as well as the type of facility where HCV testing was done. If HCV tests from more than one provider were reported for a single patient, attempts were made to contact all providers. If the provider indicated that the patient had an acute hepatitis C infection or that the patient had a negative test in the 6 months before the patient's first positive HCV test, the case was also assigned for investigation as a possible acute HCV infection. Acute HCV investigations involve more detailed collection of information from clinicians on the patient's symptoms and prior negative HCV tests, as well as patient interviews to identify risk factors.

Patients were excluded from analysis if it was learned through the investigation that the patient did not meet the inclusion criteria, if the provider did not complete the questionnaire, or if the patient had a follow-up negative HCV RNA or antibody test. Patients with subsequent negative tests were excluded because the goal of case investigations was to characterize currently infected cases. It is impossible to differentiate between antibody-positive, RNA-negative cases with resolved infection, and those with false-positive antibody tests. Since youth and young adults have a low prevalence of HCV, positive antibody tests in this age group are more likely to be falsely positive than in other age groups with higher HCV prevalence.

All analyses were conducted using SAS 9.2, Cary, NC, USA, and maps were created using ArcGIS version 10.0, Redlands, CA, USA. Statistical significance was defined as $p < 0.05$.

RESULTS

Surveillance Data

Between 2009 and 2013, there were 42,847 NYC residents newly reported with HCV. Of these, 350 (1 %) were <18-year olds; 613 (1 %) were 18–21-year olds; 1356 (3 %) were 22–25-year olds; 2492 (6 %) were 26–30-year olds; 10,230 (24 %) were 31–45-year olds; 23,219 (54 %) were 46–66-year olds; and 4587 (11 %) were >66-year olds (Table 1). Over 60 % of individuals in the 26–66-year-old age groups were male, compared with the 0–21- and >66-year-old age groups, in which close to 50 % were male (Table 1).

Figure 1 shows the average annual rates of newly reported HCV by neighborhood between 2009 and 2013 for ≤30- and 46–66-year olds. Of 26,887 non-incarcerated HCV cases in these two age groups, 25,305 (94 %) were reported with a zip code that could be assigned to a neighborhood. Neighborhoods that had significantly higher rates of HCV among ≤30-year olds versus 46–66-year olds compared with NYC as a whole were located in southwestern Brooklyn, parts of Manhattan, west-central Queens, and Staten Island.

Of 40,898 non-incarcerated HCV cases in all age groups, 32,836 (80 %) had sufficient address information to allow them to be geocoded to a census tract. Of 8062 cases not able to be geocoded, 450 (6 %) were known to be homeless. Of geocoded cases, 30,468 (93 %) were able to be joined with a census tract poverty level from the American Community Survey. For the age groups 26 and older, HCV rates in the high, very high, and highest poverty census tracts were higher than in the very low, low, and medium poverty census tracts, while in the younger age groups, rates in lower poverty census tracts were similar to or higher than rates in higher poverty census tracts. Chi-squared tests for trend were significant at the $p < 0.05$ level for the 22–25-, 26–30-, 31–45-, 46–66-, and >66-year-old age groups (Table 1).

Case Investigations

There were 210 persons ages 0–21 and 384 persons ages 22–30 diagnosed with HCV in 2013 and assigned for investigation. Of these, 192 (32 %) were excluded during the course of the investigation because: a follow-up HCV RNA test was negative ($n=82$); the patient's date of birth was reported incorrectly, and it was learned through the investigation that the patient was over 30 years old at the time of diagnosis ($n=32$); the patient had been previously reported with hepatitis C before the study time period ($n=19$); the patient was found to live outside NYC at the time of diagnosis ($n=18$); the provider was unable to be reached ($n=15$); a follow-up HCV antibody test was negative, indicating that the test was likely a false positive ($n=13$); the test result was reported incorrectly and the patient never tested positive for HCV ($n=9$); or the provider refused to fill out the questionnaire ($n=4$). The remaining 126 cases ages 0–21 and 276 cases ages 22–30 were included for analysis.

Table 2 shows demographic and clinical characteristics of the 402 (68 %) non-excluded cases. The highest percentage of cases were non-Hispanic white. The most commonly reported birth country other than the USA was the former Soviet Union. Of 21 cases born in the former Soviet Union, 16 (76 %) lived in southwestern Brooklyn, one of the areas with high rates of HCV among persons 30 and younger. The reason for HCV testing most frequently indicated by the providers was screening of asymptomatic patients with reported risk factors. Fifty-nine percent of cases had a positive HCV RNA test done, and the remaining 41 % of cases did not

TABLE 1 Characteristics of NYC residents reported with HCV, 2009–2013

	Age group							Total
	<18 years	18–21 years	22–25 years	26–30 years	31–45 years	46–66 years	>66 years	
<i>n</i> (% of total)	350 (1 %)	613 (1 %)	1356 (3 %)	2492 (6 %)	10,230 (24 %)	23,219 (54 %)	4587 (11 %)	42,847
% Male ^a	53 %	48 %	56 %	62 %	67 %	66 %	51 %	64 %
Average number of persons newly reported with HCV per 100,000 population per year by census tract poverty level ^b								
Very low	1.7	15.9	26.8	28.3	32.1	81.9	46.8	41.5
Low	3.1	19.2	32.3	31.9	52.8	109.7	53.8	54.9
Medium	3.4	18.1	32.4	40.5	66.8	142.7	79.8	67.5
High	3.5	17.9	30.2	50.9	84.7	194.8	104.1	82.1
Very high	2.7	17.7	40.2	59.1	111.1	262.6	114.6	100.4
Highest	2.7	23.7	47.7	90.7	153.0	337.2	118.2	118.9
Chi-squared test for trend <i>p</i> value	0.92	0.22	0.0001	<0.0001	<0.0001	<0.0001	<0.0001	–

^aDiffered significantly across age groups; chi-squared $p < 0.0001$

^bCensus tract poverty levels are defined as the percentage of residents with household incomes below 100 % of the federal poverty level, per the 2008–2012 American Community Survey: very low poverty, <5 %; low poverty, 5 to <10 %; medium poverty, 10 to <20 %; high poverty, 20 to <30 %; very high poverty, 30 to <40 %; highest poverty, ≥40 %

FIG. 1 Rate of new reports of hepatitis C among ≤30- and 46–66-year olds by neighborhood, 2009–2013. Asterisks denote neighborhoods that had a significantly higher rate of HCV among ≤30- versus 46–66-year olds compared to NYC overall.

have an RNA test done. Providers were asked when they thought the patient was first infected with hepatitis C; for 74 % of cases, this question was marked “Unknown” or left blank, and providers indicated that the remaining cases were infected in the past 12 months (8 %), 1–5 years ago (9 %), or over 5 years ago (8 %).

Of the 402 cases investigated, 22 (5 %) were assigned for investigation as potentially acute hepatitis C cases. Of these, six met the CDC/CSTE case definition for acute HCV infection,²⁴ which requires (1) symptoms of acute hepatitis and either jaundice or elevated serum alanine aminotransferase (ALT) levels >400 IU/L, or (2) a documented HCV antibody test followed within 6 months by a positive test.

HCV testing was most frequently done at an outpatient primary care or internal medicine office, though many tests were also done at inpatient or outpatient substance abuse and detox facilities (Table 3).

The most common risk factor reported by providers among <18-year-olds was perinatal HCV exposure, while the most common risk factor reported among individuals in the 18–30-year-old age groups was injection drug use (Table 4). Heroin was the most common drug injected, reported among 84 % of all cases with reported injection drug use. Twenty-nine percent of cases had no identified risk factors. For 21 cases born in the former Soviet Union, the most common risk factor was medical procedures outside the USA, reported among 7 cases (33 %). Three (14 %) had reported injection drug use, compared with 44 % of cases not born in the former Soviet Union (chi-squared $p=0.007$).

DISCUSSION

Nearly 5000 persons 30 and younger were newly reported to the NYC DOHMH with HCV between 2009 and 2013. People who have recently begun injecting drugs are at high risk for contracting HCV, and HCV is likely underdiagnosed in young

TABLE 2 Characteristics of ≤30-year-old investigated HCV cases, 2013 (*n*=402)

	<i>n</i> (%)
Race/ethnicity	
White, non-Hispanic	176 (44 %)
Hispanic	115 (29 %)
Black, non-Hispanic	50 (12 %)
Asian, non-Hispanic	35 (9 %)
Other	5 (1 %)
Unknown	21 (5 %)
Birth country	
USA (including Puerto Rico)	130 (32 %)
Former Soviet Union	21 (5 %)
Other	27 (7 %)
Unknown	224 (56 %)
Reason for HCV testing (not mutually exclusive)	
Screening of asymptomatic patient with reported HCV risk factors	189 (47 %)
Screening of asymptomatic patient with no reported HCV risk factors	79 (20 %)
Elevated liver function tests	67 (17 %)
Follow-up testing for previous marker of hepatitis	40 (10 %)
Routine screen, unknown if patient had symptoms/risk factors	36 (9 %)
Prenatal testing	14 (3 %)
Symptoms	13 (3 %)
Donor screening	4 (1 %)
Patient request	3 (1 %)
Dialysis	1 (<1 %)
Unknown	13 (3 %)
RNA test done	237 (59 %)
When does provider think patient was first infected with HCV?	
Past 12 months	33 (8 %)
1–5 years ago	36 (9 %)
>5 years ago	34 (8 %)
Unknown	299 (74 %)

injectors, particularly among those who are not using harm reduction services.^{25,26} Therefore, it is likely that the numbers of new HCV infections among youth and young adults are higher than the numbers reflected in routine HCV surveillance data. Rates of prescription opioid analgesic misuse and of heroin use among young people are increasing in NYC,^{27–30} and rates of HCV in young people are expected to follow. Though recent reports of increases in HCV among youth and young adults have mainly been reported in rural and suburban settings,^{5–8} the large number of young people newly reported with HCV in NYC over the last 5 years combined with an increasing pool of young injection drug users indicate that HCV in youth and young adults is also a major concern in NYC and other urban settings.

There are interesting differences in demographics between persons 30 and younger and baby boomers newly reported with HCV in NYC. The proportion of males and females among persons 30 and younger newly reported with HCV was similar, unlike among the older cases, where there were more males than females. The highest proportion of HCV cases 30 and younger (44 %) were non-Hispanic whites. The race/ethnicity distribution among these individuals was different than that seen in our previously published investigation of a sample of HCV cases of all

TABLE 3 Facilities where HCV testing was performed for investigated ≤30-year-old HCV cases, 2013

	<i>n</i> (%)
Inpatient facility	
Jail/Prison	22 (5 %)
Medicine	37 (9 %)
Psychiatric	11 (3 %)
Substance abuse/detox	69 (17 %)
Outpatient facility	
Emergency department	15 (4 %)
Gastroenterology/infectious disease	38 (9 %)
Obstetrician/gynecologist	15 (4 %)
Primary care/internal medicine	118 (28 %)
Substance abuse/detox	35 (8 %)
Other/unknown facility	57 (14 %)

Represents responses provided by 417 providers for 402 patients tested for HCV; more than one physician questionnaire was completed for 12 patients

ages in NYC from 2009 to 2011, of which 33 % were Hispanic, 33 % were non-Hispanic black, and 21 % were non-Hispanic white.³¹ Though most cases 30 and younger with known country of birth were born in the USA, a notable percentage was from the former Soviet Union. Among the cases born in the former Soviet Union, the most commonly reported risk factor was medical procedures outside the USA. Therefore, local prevention activities may be less effective for this group.

High rates of HCV in persons 30 and younger were seen in neighborhoods in southwestern Brooklyn, Manhattan, west-central Queens, and Staten Island, and there was no clear gradient of increasing HCV rates among persons 25 and younger with increasing census tract poverty levels. This differs from the older age groups and particularly the baby boomers, for which the same neighborhoods did not have higher rates of HCV and for which HCV rates steadily increased with increasing census tract poverty level.

The most common HCV risk factor among investigated HCV cases ages 18 to 30 was injection drug use, predominantly heroin. This is consistent with the most common risk factor for HCV in older age groups and indicates that efforts should be made to prevent injection drug use among young people and to encourage safe injection practices among those who do inject.³² In particular, it is important to emphasize to young injectors that sharing cookers, cottons, and other injection paraphernalia, in addition to needles and syringes, can spread HCV.^{33–35}

Existing HCV prevention and harm reduction efforts in NYC are focused on the population with highest prevalence of HCV, the baby boomers, and may not be as effective for a younger population with different demographics and living in different neighborhoods. In particular, many of the geographic areas with the highest rates of HCV among young people have few needle exchanges and other harm reduction services compared with the rest of NYC.³⁶ The demographics of persons 30 and younger newly reported with HCV parallel those seen in recent increases in prescription opioid misuse and in heroin overdoses in young people in NYC, particularly among white, non-Hispanic young people from Staten Island and from lower poverty neighborhoods,^{27–30} and indicate that HCV intervention efforts geared toward young people should focus on these populations.

TABLE 4 Reported risk factors among investigated ≤30-year-old HCV cases, 2013

Risk factor (not mutually exclusive)	Age group					Total (n=402)
	<18 years (n=36)	18–21 years (n=90)	22–25 years (n=110)	26–30 years (n=166)		
Injection drug use (%)						
Heroin (% of all with reported injection drug use)	1 (3 %)	37 (41 %)	46 (42 %)	88 (53 %)		172 (43 %)
Intranasal drug use (%)	1 (100 %)	28 (76 %)	43 (93 %)	73 (83 %)		145 (84 %)
Ever incarcerated (%)	1 (3 %)	16 (18 %)	25 (23 %)	45 (27 %)		87 (22 %)
Ever diagnosed with an STD (%)	0 (0 %)	7 (8 %)	19 (17 %)	39 (23 %)		65 (16 %)
Men who have sex with men (%)	0 (0 %)	12 (13 %)	16 (15 %)	23 (14 %)		51 (13 %)
Tattoo outside a licensed parlor (%)	0 (0 %)	7 (8 %)	10 (9 %)	12 (7 %)		29 (7 %)
Perinatal HCV exposure (%)	0 (0 %)	6 (7 %)	3 (3 %)	13 (8 %)		22 (5 %)
Other ^a (%)	19 (53 %)	0 (0 %)	1 (1 %)	0 (0 %)		20 (5 %)
No identified risk factors (%)	7 (19 %)	12 (13 %)	18 (16 %)	26 (16 %)		63 (16 %)
	9 (25 %)	32 (36 %)	33 (30 %)	42 (25 %)		116 (29 %)

^aOther risk factors: possible exposure in a country with high HCV prevalence (n=14), other needle use (n=13), piercing outside a licensed parlor (n=10), transfusion/transplant before 1991 (n=9), frequent use of a glucometer (n=7), work in the medical/dental field (n=5), other invasive medical procedure (n=3), dialysis (n=2)

The majority of HCV cases investigated were diagnosed at primary care or substance abuse facilities and were screened because they had risk factors for HCV. Over one third of the cases had not had a confirmatory RNA test done, similar to what was seen in our previous analysis of people reported with HCV in NYC,²¹ indicating that efforts should be made to ensure that these individuals are not only screened for HCV but that they get the recommended RNA test to determine their infection status. Particularly with the availability of new antivirals to treat HCV,³⁷ efforts should be made to ensure that individuals with positive HCV RNA tests are effectively linked to care so that they can receive liver health evaluation, counseling, and interventions, as well as evaluation for antiviral treatment where indicated.

There were several limitations to these analyses. First, as most people with HCV are not diagnosed at the time of their initial infection, surveillance data for HCV reflect the time of HCV testing, not the time of initial HCV infection; also, undiagnosed persons are not included. Second, all persons with a positive HCV antibody test are included in the HCV surveillance database as HCV cases, regardless of whether they had a positive HCV RNA test. For the HCV cases among persons 30 and younger that we investigated, we were able to exclude cases with negative RNA if an RNA test was performed and we were able to obtain the lab result. However, we do not have negative RNA results for uninvestigated cases, and our surveillance criteria are based on the CDC/CSTE case definition for past or present hepatitis C.²⁰ Therefore, it is likely that some of the HCV cases included in this report do not in fact have current HCV infection. Third, we collected data only from healthcare providers; interviewing patients could have provided more complete information on risk factors and drug use. However, during a pilot project, we had a very low response rate for patient interviews.³⁸ Fourth, though we obtained data on risk factors for HCV among the cases 30 and younger we investigated, we were unable to determine exactly how each person acquired his/her HCV infection. Finally, this is a descriptive analysis and does not assess independent risk factors for HCV infection among youth and young adults.

Surveillance for HCV among youth and young adults should be a priority in both rural and urban settings; as young age is a proxy for recent infection with HCV, understanding the demographics and risk factors of young people with HCV can help to target HCV prevention efforts. Though, as noted in the paragraph above, there are limitations to using data from surveillance systems, it is important to continue collecting and analyzing these data as they are more representative of the HCV-infected population than data from clinical cohorts. Funding for HCV surveillance, particularly among youth and young adults, is essential. Our analysis provides a characterization of NYC residents 30 and younger newly reported with HCV. In contrast to the overall demographics of NYC residents newly reported with HCV, most of whom were baby boomers, these youth and young adults were predominantly non-Hispanic whites. A majority of persons 30 and younger with HCV had reported injection drug use, and high rates of HCV were seen in neighborhoods with increasing rates of prescription opioid and injection drug use among young people. Tailored interventions to decrease initiation of injection drug use among youth and young adults and to encourage safe injection practices among young people who inject drugs are needed in order to avert a new wave of the HCV epidemic among youth and young adults.

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