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KNOWLEDGE ABOUT HEPATITIS C VIRUS INFECTION AND ACCEPTABILITY OF TESTING IN THE 1945–1965 BIRTH COHORT (BABY BOOMERS) PRESENTING TO A LARGE URBAN EMERGENCY DEPARTMENT: A PILOT STUDY

Waridibo E. Allison, MBBS, PHD,* William Chiang, MD,† Ada Rubin, BA,† Lillian Oshva, MD,† and Ellie Carmody, MD*

*Division of Infectious Diseases and Immunology, Department of Medicine, New York University School of Medicine, New York, New York and
 †Ronald O. Perelman Department of Emergency Medicine, New York University School of Medicine, New York, New York
 Corresponding Address: Waridibo E. Allison, MBBS, PHD, Division of Infectious Diseases and Immunology, Department of Medicine, NYU School of Medicine, 462 First Avenue, New York, NY 10016

Abstract—Background: Hepatitis C virus (HCV) is responsible for the most common chronic bloodborne infection in the United States. The Centers for Disease Control (CDC) recently recommended screening all patients born between 1945–1965 (baby boomers) at least once for HCV infection. New York State has since mandated screening of baby boomers for HCV in nearly all patient care settings and encouraged it in the emergency department (ED). **Objectives:** This pilot study aimed to ascertain acceptability of an HCV screening test among the 1945–1965 birth cohort presenting to the ED in advance of a study investigating the prevalence of HCV infection in this birth cohort in the ED setting. **Methods:** We conducted a cross-sectional study of health knowledge about HCV and government recommendations regarding HCV testing using a convenience sample of baby boomers in an ED in a large public hospital in the New York metropolitan area. Surveys were administered via a series of semistructured interviews. **Results:** There were 81 patient participants. Fifty-two percent of patients were born outside of the United States, 69% had a high school diploma level of education or lower, and 37% were unemployed. Patients demonstrated misconceptions about HCV transmission and curability and poor knowledge about the necessity of testing in their age cohort. Knowledge that “HCV can cause the liver to stop working” was significantly associated with acceptance of testing. **Conclusions:** Baby

boomers showed limited knowledge about the necessity of HCV screening in their age group, but testing for HCV infection in the ED was acceptable for the majority. © 2016 Elsevier Inc.

Keywords—acceptability; hepatitis C virus; knowledge; public health; screening

INTRODUCTION

Hepatitis C virus (HCV) is responsible for the most common chronic bloodborne infection in the United States, with an estimated 3.2 million individuals chronically infected (1). The natural history of HCV infection after exposure is that 15–40% of those exposed will clear the virus spontaneously (resolution of infection) and 60–85% will develop persistent (chronic) infection; of those chronically infected, 20–30% will develop cirrhosis over the next 20–30 years if left untreated (2).

The public health implications of HCV infection have received increasing attention in recent years (3,4). A prediction model of disease progression and mortality among Americans with prevalent HCV infection in 2005 predicted a peak between the years 2030–2035 of 38,600 cases of end-stage liver disease, 3200 referrals for liver transplant, and 36,000 deaths (4). This study

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concluded that low rates of HCV screening and treatment will likely significantly increase future morbidity and mortality from HCV infection without public health interventions to increase screening and treatment rates.

Direct-acting antivirals (DAAs) have revolutionized the treatment landscape for HCV, making cure a realistic goal for a large number of patients with chronic HCV infection (5). To effectively target populations that would achieve the greatest benefit from screening, various birth cohorts were analyzed by the United States (US) Centers for Disease Control and Prevention (CDC). The 1945–1965 birth cohort, also known as “baby boomers,” was targeted based on numerous factors, including high overall HCV prevalence, the highest prevalence of HCV infection in the non-Hispanic black population and a lower number needed to screen to prevent one HCV-related death (6). The prevalence of HCV infection in the baby boomer birth cohort is estimated to be 3.3%. This represents more than three-quarters (77%) of all adult infections. Moreover, 60% of those infected with HCV in this age group are unaware of their status. It has been predicted that targeted screening within this population could identify more than 800,000 new cases and avoid 120,000 deaths (6).

In August 2012, the CDC recommended one-time screening for HCV infection for all individuals born between 1945 and 1965. In June 2013, the US Preventive Services Task Force supported the CDC recommendation, giving it a grade B recommendation (i.e., high certainty that the net benefit is moderate or moderate certainty that the net benefit is moderate to substantial). On January 1, 2014, a new law became effective in New York State mandating screening of baby boomers for HCV in all patients receiving inpatient and primary care services at hospitals and all patients receiving primary care services from physicians, physician assistants, and nurse practitioners regardless of setting. A notable exception to this law was the emergency department (ED), where screening of baby boomers is encouraged but not mandated (7).

Limited data exist on screening uptake and outcome for HCV in the ED. For example, Capron et al. describe screening results from an Emergency Health Unit Hospital in Picardy, France, where the local prevalence was 1.1% (8). Patients with a reported risk factor received testing, but risk factors did not include being born between 1945 and 1965. Screening uptake was not reported, and the prevalence was 2.4% among those tested (11/451). A more recent study reports HCV screening specifically among the baby boomer population in an ED in Alabama (9). Of 2323 baby boomers offered testing, 88% accepted testing, and the prevalence of HCV antibody positivity in the 1529 patients tested was 170 (11%). One hundred fifty patients had RNA polymerase

chain reaction testing, and chronic HCV infection was confirmed in 102 patients (68%).

This study aimed to ascertain the level of knowledge about HCV infection and acceptability of testing for HCV infection among baby boomers presenting to a large urban, public ED >12 months after the initial CDC recommendation and within the first year of a New York State law encouraging screening in baby boomers in the ED while mandating it in other clinical settings.

METHODS

This was a cross-sectional study using a convenience sample of baby boomers in an ED in a single large public hospital with academic affiliation in the New York metropolitan area. The surveys were administered through semistructured interviews that occurred between September 15, 2014 and November 8, 2014. The institutional review boards of Bellevue Hospital Center and the affiliated New York University (NYU) Langone Medical Center approved the study. Participation was anonymous, and a waiver of documentation of consent was obtained. All subjects underwent verbal consent and were provided with a study information sheet and a CDC information sheet on HCV testing in baby boomers.

Eligible participants consisted of patients born between 1945–1965 presenting to the Bellevue Hospital Center ED. Exclusion criteria for participation were: (1) refusal of an individual to participate when approached; (2) an individual triaged as triage category 1 or 2, who by definition had a life-threatening emergency that precluded study involvement in the absence of patient duress; (3) inability of an individual to successfully negotiate use of a telephone interpreter (for example, a patient with hearing difficulties); (4) an individual with a presenting complaint that could be categorized as a mental health problem; and (5) an individual who verbally stated that they are HCV-positive when approached by the researcher.

A researcher-administered questionnaire was used to collect information from baby boomers and health care providers via a semistructured interview. Prospective patient participants were identified by the ED electronic medical record system whiteboard (a list of all patients in the ED at a particular time). On an interview day, which was defined as any time between 8 AM and 12 AM seven days per week, participants that fulfilled the inclusion criteria were selected for approach by the researcher in order of duration of stay in the ED. Potential participants were approached by consecutively selecting individuals in order of longest duration of stay first. If necessary, a phone interpreter was used for participation. Phone interpreters were used if there was a language barrier or patient preference. Family members or friends were not used as interpreters. Data were collected on paper forms

and transferred to a Research Electronic Data Capture (REDCap) database hosted by New York University (10). REDCap is a secure, web-based application designed to support data capture for research studies.

The patient questionnaire was developed based on the knowledge of HCV portion of the Hepatitis C Follow-up Survey carried out during the National Health and Nutrition Examination Survey (NHANES) from 2001–2008 (11). An expert panel consisting of two infectious disease physicians and two emergency physicians assessed the interview script for content relevance, language, and structure. The patient interview script (Appendix) consisted of three sections: sociodemographic factors, knowledge of HCV, and acceptability of testing. Hepatitis C knowledge was ascertained via either a “true or false” or “yes/no/don’t know” response to a series of statements about HCV transmission and health effects. One question about hepatitis C cure was on a five-point Likert scale (from 1 = never to 5 = always). All interview questions were closed excepting one open-ended question asking participants for their reason for a “no” response to a question about whether they would accept an HCV test if it were offered to them.

Data were analyzed using SPSS statistical software (version 17; IBM, Armonk, NY) (12). Standard descriptive statistics were used to summarize response data. The significance of comparisons between groups was assessed using a chi-squared test or Fisher’s exact test for small proportions at a significance level of $p \leq 0.05$. Odds ratios (ORs) and 95% confidence intervals (CIs) were used as measures of association. To facilitate the interpretation of Likert-scaled responses, scaled responses were collapsed into 3 categories: disagree (scale 1 and 2) neutral (scale 3), and agree (scale 4 and 5). Open responses were analyzed qualitatively, identifying key concepts emerging from the wording of the responses and condensing these into distinct themes.

There is no consensus on how to determine the sample size for a pilot study, and different methods can be used. We used the approach of a pilot study sample size of 10% of the estimated final study size (13). A final study size was estimated as follows: assuming an approximate prevalence of HCV of 10% among a population size of 44,000 unique baby boomers presenting to the Bellevue Hospital Center ED each year, a sample size of 381 was calculated to assure that the empiric estimate was within 3% of the true prevalence (true prevalence being between 7–13% at a 95% CI). At 10% of the final study size, a minimum pilot study sample size of 38 was required.

RESULTS

Of the 146 patients born who were approached and who were born between 1945–1965, 81 patients agreed to

the interview. This was just over double the minimum sample size calculated for this pilot study. Patient participant characteristics are summarized in Table 1. A third of patients had a primary language other than English but an interpreter was only required for 9 (11%) of patient participants. Almost half the patients were born outside the United States, but the majority of those foreign-born participants had lived in the US for >26 years. The majority of patient participants did not complete tertiary education and were educated to the level of a high school diploma or lower. Only 30 (37%) of patient participants were currently employed.

Patient responses to knowledge questions about HCV in baby boomers are shown in Table 2. Most understood the bloodborne risk factors for HCV transmission, but there were some misconceptions about transmission through kissing. However, only 24 (29%) identified that people born between 1945–1965 are more likely to have HCV infection than other age groups. The Likert-scaled response to the question “How often do treatments available today cure hepatitis C?” was answered correctly with “most of the time” by 21 (26%) of patients, and the same proportion of patients responded with “sometimes”; 14 (17%) responded with “never” and the same number of patients 9 (11%) responded with “almost never” and “always.”

Answering “true” to the statement “Hepatitis C can cause the liver to stop working” was significantly associated with agreeing to have an HCV test if it was offered in the ED ($p = 0.041$; OR, 3.35 [95% CI, 1.04–10.8]).

Fifty-one patients or nearly two-thirds of baby boomers interviewed (63%) found HCV testing in the ED acceptable and would agree to being tested for HCV in the ED. Reasons for patient refusal to accept

Table 1. Patient Participant Characteristics

Characteristic	n (%)
Sex	
Male	52 (63)
Female	29 (35)
Place of birth	
USA	42 (52)
Other	38 (47)
No. of years in USA if born outside USA	
≤ 25 years	14 (17)
≥ 26 years	24 (30)
Education level	
Associate degree or higher	25 (31)
High school diploma or lower	56 (69)
Primary language	
English	53 (65)
Spanish	15 (18)
Other	14 (17)
Employment	
Employed	30 (37)
Unemployed/Retired/Unable to work	51 (62)

Table 2. Responses to HCV Knowledge Questions in Patients Born 1945–1965

	True,* n (%)	False,* n (%)	Don't know,* n (%)
If someone is infected with hepatitis C virus, they will most likely carry the virus all their lives unless treated	58 (71)	6 (7)	17 (21)
Hepatitis C can cause the liver to stop working	66 (81)	3 (4)	12 (15)
Hepatitis C can lead to liver cancer	47 (57)	4 (5)	29 (35)
Someone with hepatitis C can look and feel fine	50 (61)	15 (18)	16 (20)
You can get hepatitis C by getting a blood transfusion from an infected donor	73 (89)	4 (5)	4 (5)
You can get hepatitis C by shaking hands with someone who has hepatitis C	9 (11)	65 (79)	7 (9)
You can get hepatitis C by kissing someone who has hepatitis C	34 (42)	37 (45)	10 (12)
You can get hepatitis C by having sex with someone who has hepatitis C	56 (68)	13 (16)	11 (13)
You can get hepatitis C by being born to a woman who had hepatitis C when she gave birth	56 (68)	7 (9)	18 (22)
You can get hepatitis C by being stuck with a needle or sharp instrument that has hepatitis C infected blood on it	76 (93)	2 (2)	3 (4)
You can get hepatitis C by working with someone who has hepatitis C	15 (18)	59 (72)	7 (8.5)
You can get hepatitis C by sharing needles used for injecting drugs even if only once many years ago	74 (90)	4 (5)	3 (4)
People born from 1945–1965 are more likely to have hepatitis C than people born before or after those years	24 (29)	25 (31)	32 (39)
There is a vaccine that can be used to prevent people from getting infected with the hepatitis C virus	46 (56)	14 (17)	21 (26)
Hepatitis C is curable	42 (51)	22 (27)	17 (21)
New medications have become available in the past three years that have made hepatitis C easier to treat	63 (77)	3 (4)	15 (18)

* Correct responses for each question are indicated in bold.

testing were conviction that they were not infected with HCV, being in a hurry to leave the ED, fear of needles and not wanting to have extra blood tests done, not feeling well enough, and wanting to focus on their presenting medical condition. Not feeling well enough or wanting to deal with their presenting medical conditions first were the most common reasons for refusal.

DISCUSSION

Knowledge about HCV infection and acceptability of testing specifically in baby boomers presenting to the ED setting has not been explored extensively in published literature. The ED has been an important clinical setting for screening for other infectious diseases where early linkage to care and treatment is important, most notably HIV infection. Screening for HIV infection in the ED has been mandated by law in New York since 2010, with varying compliance with the law across the state and linkage to care remaining a challenge (14). We suggest that the ED will become a similarly important clinical setting for screening for HCV infection. There is some overlap in the risk factors for both of these infectious diseases, and the populations affected often have fragmented primary care, making the ED an important access point for high-risk individuals. Additional studies evaluating the prevalence of HCV infection in baby boomers presenting to the ED and linkage to care after diagnosis in the ED are warranted.

Implementation of HCV testing in the ED will require knowledge of facilitators and barriers to patient

acceptability of testing and facilitators and barriers to offering of testing for ED health care providers, and our study contributes to this knowledge. A rapid HCV test has been approved by the Food and Drug Administration (FDA) (OraQuick HCV Rapid Antibody Test, OraSure Technologies, Bethlehem, PA) is available and may facilitate HCV screening in the ED with results available after 20 minutes. This test can be done with a finger stick blood sample and addresses a patient concern that emerged in our study: unnecessary venipuncture. This pilot study highlights how the unique richness of qualitative data can complement quantitative data in informing the nuances of implementation of a screening program.

Knowledge that HCV “can cause the liver to stop working” was significantly associated with accepting an HCV screening test. There was no association with answering any other HCV knowledge question correctly with patient acceptance of an HCV screening test. Forty-nine patients (61%) stated that they had a primary care provider.

Our study determined that some common misconceptions about HCV transmission and the effectiveness of treatment persist among baby boomers. Despite extensive public health promotion messages from the CDC and New York State Department of Health about HCV screening in baby boomers, absorption of these messages by the group of patients interviewed was poor. The lower socioeconomic and immigrant status of our study population may influence the penetration of government health promotion messages. Novel strategies are needed to ensure that particular groups of baby boomers are

educated about the necessity of HCV screening. Education of the 1945–1965 birth cohort about HCV was not an objective of this study; however, knowledge of participants may have improved because they were provided with the correct answers to the questions if requested and all were provided with the CDC information sheet about screening for HCV in baby boomers.

A paradigm shift has occurred in the management of HCV infection. DAAs have revolutionized treatment success and sustained virologic response rates to treatment of >90% are achievable for genotype 1 treatment-naïve patients with chronic HCV infection (5). The first fixed-dose combination oral drug for treatment of HCV infection, a combination of two DAAs, ledipasvir and sofosbuvir, was approved by the FDA in October 2014 (15). Improved treatment has increased focus on screening to link patients to care and treatment and to reduce morbidity and mortality from long-term consequences of chronic HCV infection, such as cirrhosis and hepatocellular carcinoma. More than three-quarters of patients recognized that new drugs were available that made treatment easier; however, only half believed HCV to be curable, and most were unaware of the high success rates of treatment.

Limitations

Our study has limitations. With self-reported data, reliability is dependent on the completeness and integrity of participant responses and the quality of responses is influenced by how well the participant understands the questions being asked (16). This was combated by a more labor-intensive and time-consuming process of having the questionnaires administered by researchers in an interview format. Even with a researcher-administered questionnaire some questions were not answered, resulting in missing data. For this reason, the total responses reported differ between survey components and do not always result in the total number of patient and health care provider participants. Missing data, however, were minimal. Because of the cross-sectional study design, there may be alternate explanations for the study results (17). This limitation would usually be addressed by comparing these data to similar studies in other institutions, but there are currently minimal published data on HCV screening in baby boomers in the ED, precluding this comparison. Finally, our study was conducted in a single institution in an urban public hospital and may not be generalizable to patients and health care providers in other institutional settings.

CONCLUSIONS

This study shows that among the baby boomers interviewed, knowledge that they were at increased risk of

HCV infection and should be screened was low. In addition, there were misconceptions about how HCV is transmitted and the belief that there is a vaccine available for HCV was common. Importantly for this pilot study, acceptability of screening for HCV in the 1945–1965 birth cohort presenting to an ED setting was high. Baby boomers are an at-risk group of patients on which to focus screening for chronic HCV infection. The ED is an important clinical setting that can contribute to this public health initiative.

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ARTICLE SUMMARY

1. Why is this topic important?

The 1945–1965 birth cohort (baby boomers) has been identified as being at higher risk of hepatitis C virus (HCV) infection compared to the general population. The US Centers for Disease Control and Prevention recommends that this birth cohort should be screened at least once for HCV infection. Effective new treatments for HCV infection are now available; it is important to explore all opportunities within health care settings to screen baby boomers for this infectious disease, including in the emergency department (ED).

2. What does this study attempt to show?

We wanted to find out if baby boomers find offers of HCV testing in the ED environment acceptable and the extent of their knowledge about HCV infection and their risk for having this infectious disease.

3. What are the key findings?

Baby boomers find screening for HCV in the ED acceptable, but their knowledge about HCV infection, including their risk of HCV infection, is limited.

4. How is patient care impacted?

Patient presentations to the ED represent an opportunity to screen baby boomers for HCV infection. Baby boomers found to have HCV infection can be linked to care and effective antiviral treatment.

APPENDIX: PATIENT INTERVIEW SCRIPT

INTERVIEWER INITIALS:

QUESTIONNAIRE ID:

001 YEAR OF BIRTH:

002 SEX:

003 TRIAGE CATEGORY:

004 PRIMARY LANGUAGE:

005 NEED TO USE INTERPRETER: YES NO

006 IF YES, INTERPRETER ID:

We would like to ask you a few questions about your background:

007	Where were you born?	
008	If born outside the USA, how many years have you been in the US?	
009	Employment status. Are you currently...?	<ul style="list-style-type: none"> ● Employed for wages ● Self-employed ● Out of work and looking for work ● Out of work but not currently looking for work ● A homemaker ● A student ● Military ● Retired ● Unable to work
010	What is the highest level of school that you completed? (if currently enrolled, highest degree achieved)	<ul style="list-style-type: none"> ● No schooling completed ● Nursery school to 8th grade ● Some high school, no diploma ● High school graduate, diploma or the equivalent (for example: GED) ● Some college credit, no degree ● Trade/technical/vocational training ● Associate degree ● Bachelor's degree ● Master's degree ● Professional degree ● Doctorate degree

We would like to learn what you know about hepatitis C. I will read you a series of statements. For each statement, please tell me whether you believe it to be true or false or if you do not know whether it is true or false:

011	If someone is infected with hepatitis C virus, they will most likely carry the virus all their lives unless treated	True	False	Don't Know
012	Hepatitis C can cause the liver to stop working	True	False	Don't Know
013	Hepatitis C can lead to liver cancer	True	False	Don't Know
014	Someone with hepatitis C can look and feel fine	True	False	Don't Know
015	You can get hepatitis C by getting a blood transfusion from an infected donor	True	False	Don't Know
016	You can get hepatitis C by shaking hands with someone who has hepatitis C	True	False	Don't Know
017	You can get hepatitis C by kissing someone who has hepatitis C	True	False	Don't Know
018	You can get hepatitis C by having sex with someone who has hepatitis C	True	False	Don't Know
019	You can get hepatitis C by being born to a woman who had hepatitis C when she gave birth	True	False	Don't Know
020	You can get hepatitis C by being stuck with a needle or sharp instrument that has hepatitis C infected blood on it	True	False	Don't Know
021	You can get hepatitis C by working with someone who has hepatitis C	True	False	Don't Know
022	You can get hepatitis C by sharing needles used for injecting drugs even if only once many years ago	True	False	Don't Know
023	People born from 1945–1965 are more likely to have hepatitis C than people born before or after those years	True	False	Don't Know
024	There is a vaccine that can be used to prevent people from getting infected with the hepatitis C virus	True	False	Don't Know
025	Hepatitis C is curable	True	False	Don't Know
026	New medications have become available in the past three years that have made hepatitis C easier to treat	True	False	Don't Know
027	You will have choices to answer this question: never, almost never, sometimes, most of the time or always. How often do treatments available today cure hepatitis C?		Never Almost never Sometimes Most of the time Always (circle response)	

Finally, we would like to ask you a few questions about hepatitis C testing to which you can answer yes, no, or don't know:

028	Have you ever been tested for hepatitis C?	Yes	No	Don't Know
029	Are you aware that CDC has recommended that all people born from 1945–1965 be screened for hepatitis C?	Yes	No	Don't Know
030	Are you aware that a law was enacted in New York State in Jan 2014 mandating that individuals born from 1945–1965 be offered HCV testing by health care providers?	Yes	No	Don't Know
031	Do you have a primary care doctor?	Yes	No	Don't Know
032	Have you been offered a test for hepatitis C at any time in the past?— <i>if answer is yes go to question 033, if no or don't know go to question 035</i>	Yes	No	Don't Know
033	Have you ever had a positive hepatitis C antibody test? — <i>if yes go to question 034, if no go to question 035</i>	Yes	No	Don't Know
034	Has it ever been confirmed that you have chronic HCV infection <i>If yes END OF INTERVIEW, if no go to question 035</i>	Yes	No	Don't Know
035	If you were offered a test for hepatitis C today in the emergency room would you agree to it? <i>If yes END OF INTERVIEW, if no go to question 036</i>	Yes	No	Don't Know
036	What are your reasons for not agreeing to a Hepatitis C test today? FREE TEXT RESPONSE: END OF INTERVIEW			DON'T KNOW OR >>>