

# Screening Adult Children of Hepatitis C-Infected Baby Boomers: Barriers to Testing and Prevalence Estimates

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Nearly 1 in 30 persons born from 1945 to 1965 (i.e., baby boomers) has been infected with hepatitis C virus (HCV), with women comprising nearly half of that cohort.<sup>1,2</sup> The peak incidence of HCV acquisition occurred between the 1960s and 1980s, prior to the discovery of HCV.<sup>3</sup> Due to the asymptomatic nature of HCV, many female baby boomers were infected during their childbearing years while unaware of their diagnosis until much later because of availabilities in testing.<sup>4,5</sup>

Since 1998, HCV testing has been recommended for people born to HCV-infected mothers. However, public

health campaigns promoting HCV screening and treatment for high-risk populations often ignore the children of baby boomers.<sup>5</sup> Even with recommendations for universal testing,<sup>6</sup> many people decline if they do not recognize their risk, which may be as high as 5% (meaning up to 50,000 adult children of baby boomer mothers may be infected yet unaware).<sup>7</sup> Yet data in this population are lacking. We sought to evaluate maternal knowledge about HCV acquisition and transmission and barriers to risk-based screening in an urban health care setting.

Abbreviations: Ab, antibody; HCV, hepatitis C virus; IQR, interquartile range; IRB, institutional review board.

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This study was supported by grants from Gilead Sciences (to D.G.).

Potential conflict of interest: Dr. Goldberg's institution receives grants from Merck, Gilead and AbbVie.

Received February 21, 2020; accepted April 22, 2020.

Additional Supporting Information may be found at [onlinelibrary.wiley.com/10.1002/cld.985/supinfo](https://onlinelibrary.wiley.com/10.1002/cld.985/supinfo).

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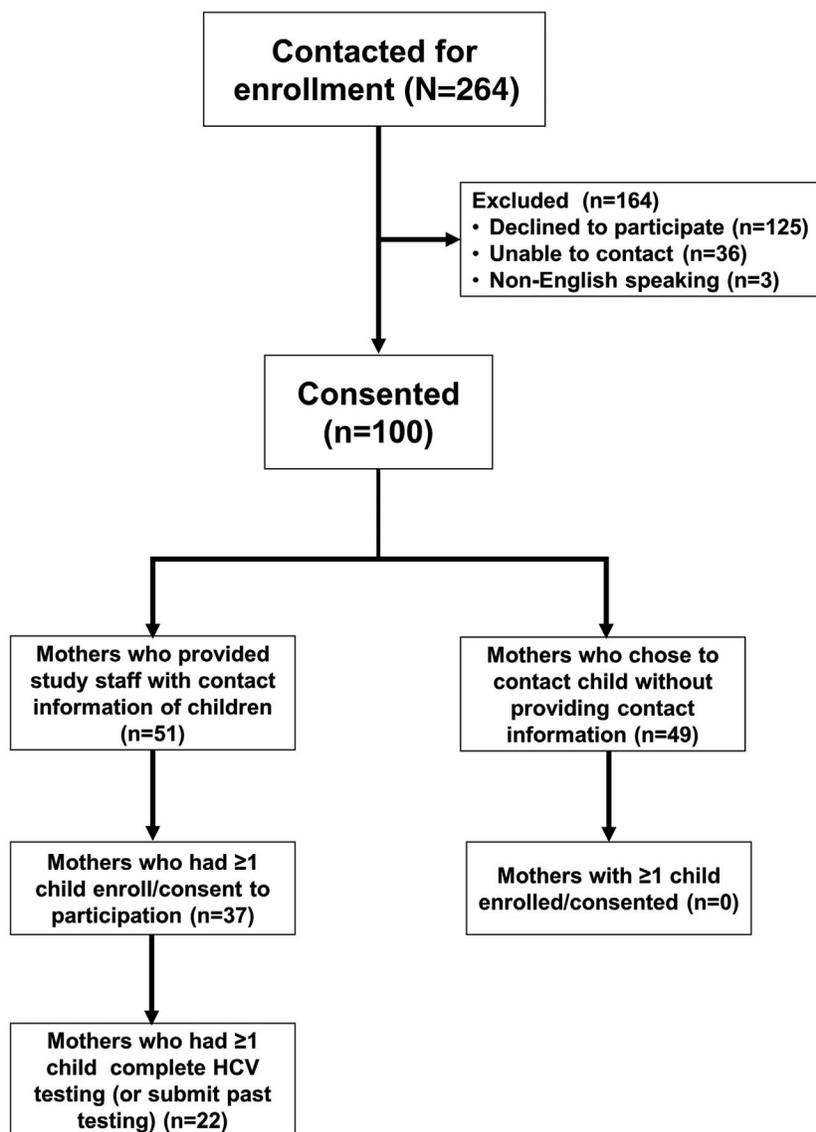
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**METHODS**

This study was conducted at the University of Pennsylvania from May 2017 to April 2019 after approval by the institutional review board (IRB). Funding was provided by Gilead Sciences, but the design, conduct, and analyses were conducted by the study authors.

Our target population was split into two arms: (1) female patients from the Penn Hepatology clinic born between 1945 and 1965 with active or prior HCV, and  $\geq 1$  living child older than 18 years; and (2) children of the mothers from the first cohort who were  $\geq 18$  years of age.

Potential arm 1 subjects (mothers) were identified through the electronic medical record and patient lists from the hepatology pharmacist and transplant team. Mothers were approached in person or by telephone, and if they consented, answered a short survey (see Supporting Information). Mothers were given one of three options for contacting their children: (1) mothers provide contact information to study staff, (2) mothers contact their children and ask them to contact the study staff, or (3) mothers first contact their children and then notify the study staff to contact them. Arm 1 subjects were provided with IRB-approved literature about HCV and compensated \$20.



**FIG 1** Flow diagram of participation of approached HCV-infected baby boomers.

Potential arm 2 subjects (adult children) were contacted by phone or in person. Once they consented, they received a short survey (see Supporting Information). HCV testing was offered at Penn or any LabCorp nationwide and was paid for by the study. Patients were mailed laboratory slips and a fact sheet about HCV. If subjects had been previously tested, they were able to participate by providing prior results. After completing testing, subjects were compensated \$20. In the event a subject tested positive and could not afford treatment, Gilead provided free treatment under primary investigator supervision.

**RESULTS**

Of 264 women, 100 (37.9%) consented, and 51 provided contact information for their children (Fig. 1). Consent rates did not differ by race ( $P = 0.8$ ). There were key differences in black versus white mothers (Table 1).

**Maternal Knowledge About HCV**

More than 40% (43/100) of mothers stated they did not know their mode of HCV transmission, and the majority (60%) were unsure when infection might have occurred. White mothers were significantly more likely to believe they had contracted HCV prior to pregnancy compared with black mothers (26.2% [11/42] versus 6.9% [4/58];  $P < 0.001$ ). Of 44 women who reported intravenous drug use, 25 (56.8%) denied this was a possible mode of their acquiring HCV. The vast majority (86%) stated their children were already aware of their mother’s HCV status, yet

more than half (59%) did not know that HCV could be transmitted from mother to child. White mothers were significantly more likely to report this knowledge compared with black mothers (57.1% [24/42] versus 29.3% [17/58];  $P = 0.005$ ). None of the other factors in Table 1 were associated with maternal knowledge.

**Maternal Preferences for Contacting Children**

A numerically higher proportion of black mothers did not want to provide their children’s contact information (38.1% [16/42] versus 56.9% [33/58],  $P = 0.06$ ). Women who consented to participate in person were significantly more likely to provide their children’s contact information (64.7% [22/34] versus 43.9% [29/66] of phone consents;  $P = 0.049$ ).

The most common reasons not to provide their children’s contact information were as follows: (1) they did not believe they acquired HCV prior to pregnancy because they were diagnosed many years later, (2) they did not believe their children could have HCV from maternal transmission, and (3) they assumed their children had been tested.

**Enrollment of Adult Children**

Of the 49 mothers who consented on the condition they contact their adult child(ren) first, no children contacted the study team.

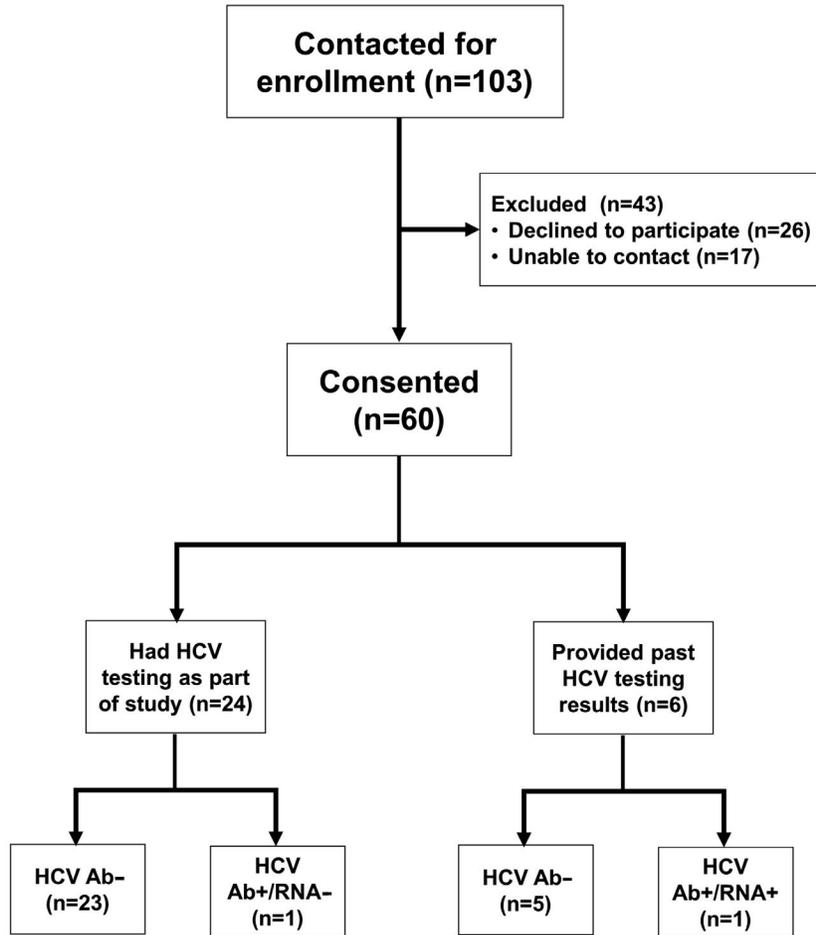
The study team was provided contact information for 103 children—86 (83.5%) were reached, and 60 (69.8%)

**TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF 100 CONSENTING BABY BOOMER MOTHERS**

Variables	Black Race (n = 58)	White Race (n = 42)	P
Age, years, median (IQR)	63 (59-65)	65 (59-69)	0.22
Hispanic ethnicity, n (%)	3 (5.2)	2 (4.8)	0.93
Highest level of education, n (%)			0.02
High school	38 (65.5)	17 (40.5)	
College	18 (31.0)	19 (45.1)	
Graduate degree	2 (3.5)	6 (14.3)	
Reported household income, n (%)			<0.001
<\$35,000	37 (63.8)	15 (35.7)	
\$35,000-\$50,000	9 (15.5)	6 (14.3)	
\$50,001-\$100,000	1 (1.7)	6 (14.3)	
>\$100,000	0 (0.0)	7 (16.7)	
History of injection drug use, n (%)	26 (44.8)	18 (42.9)	0.82
History of intranasal drug use, n (%)	22 (37.9)	15 (35.7)	0.82
History of blood transfusion, n (%)	18 (31.0)	26 (61.9)	0.001
History of tattoo, n (%)	12 (20.7)	14 (33.3)	0.16
No. of children, median (IQR)	3 (2-4)	2 (1-3)	0.004
Active HCV, n (%)	19 (32.8)	7 (16.7)	<0.07
History of liver transplant, n (%)	8 (13.8)	11 (26.2)	0.12
Treatment naïve, n (%)	9 (15.5)	6 (14.3)	0.86

consented (Fig. 2); their characteristics did not differ by race (Table 2). Of the 60 who consented, 30 (50%) completed HCV testing (this includes 6 who provided past results): 28 (93.3%) were HCV antibody (Ab) negative, 1

(3.3%) was HCV Ab positive HCV RNA negative, and 1 (3.3%) was HCV RNA positive (HCV diagnosed concurrent with study initiation and the child first approached the study staff).



**FIG 2** Flow diagram of adult children of baby boomer mothers approached for participation.

**TABLE 2. DEMOGRAPHIC CHARACTERISTICS OF 60 CONSENTING CHILDREN OF BABY BOOMER MOTHERS**

Variables	Black Race (n = 37)	White Race (n = 23)	P
Age, years, median (IQR)	32 (28-41)	34 (29-44)	0.62
Hispanic ethnicity, n (%)	4 (10.8)	2 (8.7)	0.84
Highest level of education, n (%)			0.16
High school	17 (46.0)	9 (39.1)	
College	18 (48.7)	9 (39.1)	
Graduate degree	2 (5.4)	5 (21.7)	
Reported household income, n (%)			0.38
<\$35,000	8 (21.6)	5 (21.7)	
\$35,000-\$50,000	11 (29.7)	9 (30.1)	
\$50,001-\$100,000	5 (13.5)	6 (26.1)	
>\$100,000	6 (16.2)	1 (4.4)	
History of injection drug use, n (%)	0 (0.0)	2 (8.7)	0.07
History of intranasal drug use, n (%)	1 (2.7)	3 (13.0)	0.12
History of blood transfusion, n (%)	5 (13.5)	1 (4.4)	0.25
History of tattoo, n (%)	25 (67.6)	20 (87.0)	0.09

Of the 14 who declined consent, their reasons included the following: (1) they believed they would already know if they had HCV ( $n = 6$ ), (2) they thought they were previously tested ( $n = 5$ ), and (3) going to a laboratory was inconvenient ( $n = 4$ ). For the 30 who failed to complete testing, reasons included the following: (1) too busy ( $n = 12$ ); (2) lost LabCorp paperwork ( $n = 10$ ); (3) forgot ( $n = 8$ ); and (4) belief that if they had HCV, they would know ( $n = 4$ ).

## CONCLUSIONS

In this study of HCV-infected baby boomer women, we demonstrated limited knowledge of HCV and an unwillingness or lack of understanding about the implications of potential maternal-fetal transmission. Despite education, fewer than 40% of women consented, and of those, nearly half refused to provide contact information for their children, and none of their children followed up with study staff. Even among children who were educated and offered free testing and treatment, 30% refused consent, and only half completed testing. This study highlights key barriers to risk-based HCV screening in this population with important racial differences in HCV knowledge and completion of testing.

Prior studies evaluating stigma and knowledge about HCV have not focused on HCV-infected women.<sup>8-13</sup> We found that HCV-infected baby boomer women did not demonstrate a strong grasp of HCV, despite being followed by a hepatology provider for years to decades. Nearly 60% were not aware that HCV could be transmitted from mother to child, and because their HCV was diagnosed years after acquisition, many failed to acknowledge they could have acquired HCV prior to having children.

Trust seemed to play a role in maternal willingness to provide their children's contact information, because those who consented in person were more likely to provide contact information. It is more difficult to assess whether trust factored in among the participating children, because only 6 of 60 consented in person (nearly all lived in the Philadelphia metropolitan area).

Given that HCV may be transmissible in up to 5% of pregnancies, and 3% in our series, barriers to risk-based testing represent a public health concern. Our data on low rates of HCV testing of children born to HCV-infected women validate data from a prior study conducted in

Philadelphia among HCV-infected women who had a child between 2011 and 2013. Of 500 women who had a child born during that period, fewer than 20% of children subsequently had recommended HCV testing by the end of follow-up in 2015.<sup>14</sup> Most children of HCV-positive women had no idea that HCV was transmissible from their mothers. Even armed with educational material, adult children showed little urgency in completing testing. The resistance to testing among a high-risk group that was offered free testing and treatment highlights the challenges in the broad implementation of recently recommended universal HCV screening of all adults. Although recent recommendations for universal HCV testing of adults hold promise for increasing HCV screening rates, in part by simplifying the process of determining who should be tested, our data serve as a cautionary tale of potential barriers that may arise in the acceptance of HCV screening by patients without any identifiable risk factors.

This study had limitations. First, most data were self-reported, and for mothers, some questions addressed events many years prior and/or are often stigmatized. Second, we asked for approximate years of risk factors for HCV (e.g., drug use), but we did not ask for the year of the earliest live birth. Finally, income may have had an impact on mothers who agreed to participate but failed to provide contact information.

This study highlights a lack of knowledge regarding HCV and its modes of transmission. This could portend future challenges with universal HCV testing, especially among those without any risk factors. Interventions to overcome barriers to testing, especially among those with a lack of understanding of HCV and risk factors for acquisition, are needed to eradicate HCV.

## CORRESPONDENCE

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