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Lessons Learned From Exploratory Research About Viral Hepatitis

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Abstract

The Centers for Disease Control and Prevention conducted exploratory research as part of planning a national education campaign to raise awareness about viral hepatitis in the United States. The purpose of this qualitative research was to assess the baseline knowledge, attitudes, and screening behaviors of four population groups. Sixteen focus groups were conducted during a 6-week period in the fall of 2009, with a total of 119 adults aged 35 to 60 years in Boston, Massachusetts; Chicago, Illinois; and Houston, Texas. The groups were stratified by Asian Americans, African Americans, gay or bisexual men, and general population. Group size ranged from three to nine participants, and each session was approximately 90 minutes in length. Both awareness and knowledge of viral hepatitis were low among all participants, including those at increased risk for the disease. Little was known about the different types of hepatitis, risk factors, or how the viruses are transmitted. Regarding the last, many indicated that the disease was airborne. In addition, participants incorrectly assumed that if they had viral hepatitis, they would have symptoms and know they were infected. Many participants also believed that they had been tested for the disease since their health care providers routinely “test their blood.” The findings indicate that significant and concerted educational efforts are needed to improve basic knowledge of viral hepatitis, as well as knowledge about transmission, risk factors, screening, and treatment. As a result, a general awareness and education campaign must precede and support efforts to encourage screening.

Keywords

viral hepatitis; exploratory research; formative research; focus groups; message testing; lessons learned

An estimated 4.5 million Americans are living with viral hepatitis, and the disease claims approximately 15,000 people from associated liver disease and liver cancer each year (Centers for Disease Control and Prevention [CDC], 2010; Institute of Medicine [IOM], 2010). The IOM recently released a report titled “Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C,” which identified critical factors that contribute to this unnecessary disease burden. Among its findings, the IOM reported

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that public awareness about the disease is low, many people do not know they are at risk, and approximately 65% to 75% of people with chronic viral hepatitis are unaware of their infection (IOM, 2010).

As part of planning educational strategies to address the IOM's (2010) findings, the CDC, Division of Viral Hepatitis, conducted exploratory research with consumers to gauge knowledge and attitudes about viral hepatitis and to test patient education materials. Viral hepatitis can be a complicated set of diseases to understand, and part of the research was designed to assess what consumers did and did not know about the disease. "Hepatitis" technically means inflammation of the liver and is most often caused by a viral infection. The most common types of viral hepatitis in the United States are hepatitis A, hepatitis B, and hepatitis C. Although they all attack the liver and cause similar symptoms, the hepatitis viruses are not related to one another and have different modes of transmission. Hepatitis A is transmitted from ingestion of food or water contaminated with fecal matter from an infected person, whereas hepatitis B is transmitted through contact with an infected person's blood, semen, or vaginal fluids. Hepatitis C is a blood-borne virus that is most commonly transmitted through percutaneous exposure to infected blood (American Academy of Pediatrics, 2009; CDC, 2010; IOM, 2010).

When a person is first infected with viral hepatitis, he or she may not be aware of the infection, as it can sometimes occur with few or no symptoms. In other instances, the person may experience a serious illness lasting months. Hepatitis B and hepatitis C can lead to a chronic or lifelong infection, which can cause serious health problems, including liver damage, cirrhosis, liver cancer, and even death (CDC, 2010; IOM, 2010; Perz, Armstrong, Farrington, Hutin, & Bell, 2006). Many people with chronic hepatitis are unaware that they are infected, and symptoms can take decades to manifest (IOM, 2010; Ly et al., 2012; Rein et al., 2012). Specific blood tests are available to diagnose each type of hepatitis. Hepatitis A and hepatitis B can be prevented by vaccination, but there is no vaccine available for hepatitis C (American Academy of Pediatrics, 2009; CDC, 2010).

METHOD

Focus groups can be a useful means of qualitatively exploring attitudes, behaviors, and beliefs when little is known about the phenomenon of interest (Krueger & Casey, 2009). Resources for the prevention and control of viral hepatitis are extremely limited, and as a result, research about attitudes, behaviors, and interventions is lacking (IOM, 2010; Task Force on Community Preventive Services, 2005). The exploratory research was conducted during a 6-week period in the fall of 2009 and used focus group methodology for data collection. After institutional review board approval was obtained for the research, the CDC contracted with professional consumer research companies located in Boston, Massachusetts; Chicago, Illinois; and Houston, Texas, to recruit participants and provide focus group facilities. In all, 16 focus groups were conducted in the three cities. The groups were stratified by Asian Americans, African Americans, general population, and males self-identifying as gay or bisexual (see Table 1).

Groups were stratified to represent populations with higher than average rates of viral hepatitis. Gay men have higher rates of both hepatitis A and B than the general population, with an estimated 10% of new cases of hepatitis A and 20% of new hepatitis B cases occurring in gay or bisexual men (CDC, 2010). Gay men are also at risk for hepatitis C if they have used injection drugs or have HIV (IOM, 2010; Workowski & Berman, 2010). Chronic hepatitis B disproportionately affects Asian Americans, especially those born in countries where the disease is endemic, with Asian Americans accounting for almost 50% of chronic hepatitis B cases (Ayers, Juon, Lee, & Park, 2010; CDC, 2009; IOM, 2010; Ly et al., 2012). African Americans are disproportionately affected by viral hepatitis and have the highest rates of acute hepatitis B in the United States (IOM, 2010) and are twice as likely to be infected with chronic hepatitis C as Caucasians (Armstrong et al., 2006). Hepatitis C also is believed to affect about 1% to 2% of the general population, but those born between 1945 and 1965 have the highest rates of infection (Armstrong et al., 2006; CDC, 2010; IOM, 2010; Rein et al., 2012). As such, participants in the general population group were selected to include a majority of persons from this age cohort.

All focus groups were held at the research company's focus group facilities in urban or suburban areas of the selected cities. Each of the selected companies maintain large lists (50,000–250,000 in size) of prescreened adults who have volunteered demographic information and consented to be recruited for research projects, including focus groups. Facilities contacted individuals by e-mail and asked if they would be interested in participating in a health-related focus group scheduled for a particular day and time. If a person expressed interest, he or she was screened by telephone interview for eligibility. Eligible participants were between the ages of 30 and 63 years, had no history of liver disease or major illnesses, had health insurance, had at least a high school education, and neither they nor their families had worked in health care industries. The facilities used quota sampling for the focus groups and recruited 10 to 12 interested and available persons. Once a group was filled, the recruitment for that particular group was halted. The goal was to have nine individuals in each focus group, with extra individuals recruited to account for no-shows. Individuals were paid an honorarium of \$80 for participation.

Across the three cities, a total of 119 people consented to participate in the focus groups. Participants ranged in age from 31 to 63, with an average age of 43.9 years, and 56% were male. Approximately 41% of the participants had completed college, and 24% had postgraduate training. Individuals recruited for the specific groups had to self-identify as a gay or bisexual man, African American, or Asian American. Asian American participants represented eight different ethnicities. The general population and gay/bisexual men groups consisted primarily of Caucasians but also included individuals identifying as African American, Latino, and Filipino. Groups ranged in size from three to nine participants, and each session lasted approximately 90 minutes. (The one group of three individuals resulted from severe weather that prevented most of the participants from being able to drive to the facility.) Each group was led by a professional moderator who was demographically similar to the four population groups selected for participation.

The moderator guide was based on constructs from several value expectancy theories, including the health belief model, theory of planned behavior, and social cognitive

theory (Glanz, Rimer, & Viswanath, 2008). These theories are commonly used in health promotion, and they provided a range of constructs to assess their relevance and salience given the exploratory nature of the research. Questions were designed to elicit basic knowledge and awareness; perceptions of susceptibility, severity, and preventive behaviors (health belief model); subjective norms (theory of planned behavior); and behavioral outcomes, expectancies, and normative beliefs (social cognitive theory) about vaccination and screening. Exploratory questions based on these theories and constructs included the following: What is hepatitis? What causes hepatitis? What are ways to prevent hepatitis (behavioral capacity)? How would someone know he or she has hepatitis (outcomes)? What happens if someone gets hepatitis (outcomes and severity)? Who gets hepatitis and are there any particular groups at risk (susceptibility and expectancies)? Has anyone talked to you about vaccination or testing (subjective norms)? Have you got vaccinated, and if so, why (outcomes, benefits, and barriers)? (Glanz et al., 2008). Following the exploratory discussion, CDC hepatitis educational materials were then reviewed, which provided an opportunity to further discuss the key content areas listed above.

One CDC employee observed the groups from behind a one-way glass partition and took detailed notes in addition to the audiotaped and subsequent transcriptions. Two researchers used rapid assessment procedures and a coding shell organized by topic and the constructs identified above. Important themes and subthemes, or lack thereof, were identified independently from the transcripts and notes and were then discussed together. Transcripts were analyzed by group, and when little differences were identified, the groups were merged according to topic and construct. Lessons learned are presented below.

RESULTS

Lesson 1: Knowledge About Viral Hepatitis Is Low

Overall knowledge and awareness about viral hepatitis were low. In every group, participants lacked basic knowledge about the disease and how it is transmitted, prevented, and treated. When asked what came to mind with the word *hepatitis*, no single theme emerged. Responses ranged from airborne, virus, bacteria, yellow eyes, scary, breathing problems, and bad food. Beliefs about prevention were inconsistent and contradictory. Ways to prevent the disease included hand washing, not sharing needles, using a condom, and “educating yourself about what to do.” Vaccination as a way to prevent the disease did not come up other than as a question—“I think you can get a shot for it?” Although some participants were aware of different types of hepatitis, most could not describe differences between types. Furthermore, a few people thought that hepatitis A was the least serious form of the disease, followed by hepatitis B, and then hepatitis C, which was thought to be the most serious of the three.

Lesson 2: Viral Hepatitis Nomenclature Is Confusing

Viral hepatitis is a complicated set of diseases that often uses complex, scientific nomenclature. It was very apparent that the typical scientific language used within the field and on CDC’s educational materials was confusing to participants. For example, participants reported that HAV, HBV, and HCV (common abbreviations for the various hepatitis viruses)

were confusing and unclear. The terms *acute infection* and *chronic infection* were often misunderstood and interpreted by some participants as two different diseases. The fact that hepatitis virus *infection* starts as a “short-term viral infection” and then, for some, progresses to a “chronic, lifelong infection” that can cause hepatitis the *disease* was not easily understood. Distinguishing between infection and disease seemed too nuanced and confusing to participants. For participants, the bottom line about hepatitis was that it was caused by a virus, that it could be short or long term, and that getting it was not good for a person’s health. Given that basic knowledge of viral hepatitis was low, it should be of no surprise that using typical scientific nomenclature added unnecessary nuance, complexity, and language clutter.

Lesson 3: Knowledge About Vaccines Is Low

A common theme among participants was that they knew very little about the disease and vaccination. When the moderator probed if viral hepatitis could be prevented, a vaccine was only occasionally included in the long list of possible ways to prevent the disease. When participants later read educational materials describing the vaccine, they reported some familiarity with the hepatitis vaccines. Without the text, they neither knew which types of hepatitis could be prevented through vaccination, nor for whom the vaccine was recommended. When asked if they had gotten vaccinated for viral hepatitis, many participants (other than many of the gay men) were unsure if or when they had received the vaccine. A common theme that emerged was uncertainty about which vaccines they had received, when they had received them, and for what reasons. A few of the younger participants remembered getting the hepatitis vaccine for college entry, and several mothers remembered their children getting the hepatitis vaccine. Although not explicitly asked, none of the participants expressed concern about the safety of the vaccines. A more commonly held belief was that vaccinations result in preventing disease and are therefore a good thing. This is markedly different from vaccine safety concerns that are common when children are involved. Last, after reading the educational material about the vaccine, some participants wanted to know how long the vaccine offered protection and if a booster shot was necessary. A few participants knew that the tetanus vaccine required a 10-year booster and wondered if the same was true for the hepatitis vaccines.

Lesson 4: Stigma Regarding Viral Hepatitis Abounds

The lack of basic knowledge about viral hepatitis appeared to contribute to stigma and stereotypes surrounding the disease. When asked who gets hepatitis, a common theme was that “other people” were the ones infected with hepatitis. When asked who was at risk for hepatitis, the general population group differed from other groups when expressing their attitudes and beliefs. These participants brought up a long list of different types of people who get hepatitis, such as those who have a certain lifestyles that include alcohol and drugs, musicians and bands, people who get tattoos, and even racial/ethnic groups such as African Americans and Hispanics. When asked if they knew anyone with hepatitis, a few people cited friends or family members, but the most common response was recognition of celebrities with hepatitis C. Pamela Anderson, for instance, was mentioned in every group. Responses to the question “who is at risk?” clearly indicated that hepatitis was associated

with negative and stigmatized behaviors. Interestingly, other factors, such as “eating bad food,” healthcare-acquired outbreaks, or perinatal transmission were never mentioned.

Lesson 5: Symptoms Are Believed to Tell All

Participants across all of the focus groups had low knowledge and understanding of viral hepatitis symptoms. When asked how a person would know if he or she was infected with viral hepatitis, some said he or she would have symptoms, with “yellow eyes” most frequently mentioned. Although jaundice is a common symptom of acute infection, participants were surprised to learn from the fact sheets that viral hepatitis is often asymptomatic and that symptoms could include nausea, loss of appetite, fever, joint pain, and fatigue. Participants were also unaware that symptoms of chronic hepatitis could take up to 30 years to develop and frequently arise only after damage to the liver has already occurred. Even after reading the fact sheets, many participants also falsely concluded that without symptoms, there was no disease and the virus could not be detected in their blood.

Lesson 6: Participants Believe They Have Already Been Tested for Viral Hepatitis

Knowledge and understanding of viral hepatitis testing mirrored the low levels of general disease knowledge. When asked how a person would know if he or she was infected with viral hepatitis, a common but false theme was that participants believed that they were tested for hepatitis as part of their regular physical exams. Participants were unaware that testing for viral hepatitis requires specific blood tests that are not typically part of routine blood panels.

Lesson 7: The Link Between Viral Hepatitis and Liver Cancer Is Unknown

Many participants were unaware of the severity of hepatitis C, including the virus’ link to liver cancer. In addition, participants were not aware that the disease could cause severe health problems, including cirrhosis, liver failure, or death. The prevailing theme represented was that if the disease was serious or a significant problem, then people would hear more about it, doctors would bring it up, and the issue would be in the popular media. As one participant said, “It’s not like its cancer or heart disease.”

Lesson 8: Groups at Risk Were Unaware of Their Risk

Although some of the groups were stratified specifically to represent populations at risk for viral hepatitis, most participants did not feel susceptible to the disease. As a group, gay and bisexual men were the most knowledgeable about hepatitis and their specific risk for hepatitis A and B. The knowledge level of this group was one of the major differences between groups. Despite their higher levels of knowledge and understanding of the disease, however, gay and bisexual participants still perceived risk for infection to be most commonly, and almost solely, associated with young gay men. Even though more than 50% of Americans infected with chronic hepatitis B are Asian Americans (IOM, 2010; Ly et al., 2012), Asian American focus group participants seemed largely unaware of this fact. They were reluctant to see Asians as a risk group and expressed surprise that the highest rates of chronic hepatitis B infection were in Asian countries. African American participants

also were unaware that they were disproportionately affected by hepatitis C and were quick to note the lack of public education targeted toward their community.

DISCUSSION

The lessons learned from CDC's exploratory research have major implications for research and practice. Baseline understanding of viral hepatitis among the focus group participants was much lower than anticipated, and the language used to describe the diseases was not easily understood. When professionals are immersed in a particular health issue, it can be easy to lose sight of how others unfamiliar with the issue, particularly consumers, view and interpret the specific language associated with that disease. Although a health educator must strive for precision when presenting health information, scientific accuracy must be supported and upheld with clear, simple, and appropriate language that aids consumers' comprehension of educational materials. As a result of the findings and conclusions, one important outcome of this study was modification of the educational materials produced by CDC's Division of Viral Hepatitis.

To ultimately promote testing for the disease, the research findings show that CDC's educational materials for the public need to provide information on the different types of hepatitis, how the viruses can be spread, and the consequences of undiagnosed infection. If the presence of symptoms is falsely being used by individuals as an indication of infection and a cue to action, promoting and increasing testing for viral hepatitis will not likely succeed unless this misperception can be corrected. As a result of this research, CDC has incorporated key educational messages into its existing information on the website and in educational materials. One key message is that people can live for decades without ever showing symptoms or feeling sick. Likewise, it is imperative to correct the perception that individuals would know they were infected with hepatitis because they get regular blood tests. This belief was also found in a recent survey in which 50% of participants either strongly or moderately agreed with the statement "I would know if I had hepatitis since my doctor does blood tests as a part of my regular physical exam" (Porter Novelli, 2010). Last, CDC is incorporating messages that chronic hepatitis B and C infections can lead to cirrhosis, liver failure, and even liver cancer but that treatment can often interrupt this progression and save lives. Promoting the link between hepatitis and liver cancer in educational materials may provide the public with necessary motivation to get screened for this deadly disease.

The findings from this exploratory research identified knowledge, attitude, and practices related to viral hepatitis that raise concern. The stigma associated with the disease cannot be overcome quickly or easily. Stigmatizing behaviors such as injection drug use are clearly associated with viral hepatitis. Increasing basic knowledge, including educating people about the other ways that hepatitis viruses can be transmitted (e.g., perinatal transmission, blood transfusions, lapses in health care infection control practices), may help decrease the associated stigma. Likewise, publicly profiling prominent people or celebrities who have been infected through other means may help break the stereotypes. If the educational efforts in HIV are any indication, however, only concerted education and time will make a difference in perceptions.

Despite the lessons learned through this research, the study was not without limitations. The number of groups per population strata was limited, and it is possible that more groups would have provided additional or alternative beliefs. Although qualitative research is a valuable way to gain insight into a specific population, the findings from this study cannot be generalized to a broad population. The data were analyzed using rapid analysis procedures, which could have allowed for the possibility of missing other key findings that may have been revealed in a more detailed analysis.

In conclusion, formative research is a critical step in planning any educational intervention. Practitioners can use focus groups to gain insight into topics about which little is known and apply the findings in the development of research- and theory-based messages and strategies. The focus groups were invaluable in providing insights into the audiences' knowledge and attitudes regarding viral hepatitis. As a result, CDC's educational interventions, and hopefully those of others in the field, will be improved.

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Table 1

Focus Group Participant Characteristics

	Groups			
	General Population	Asian Americans	African Americans	Gay/Bisexual Men
Cities	Chicago, Boston	Chicago, Boston	Chicago, Houston	Houston, Boston
Groups/participants	Four groups, <i>n</i> = 36	Four groups, <i>n</i> = 28	Four groups, <i>n</i> = 35	Four groups, <i>n</i> = 20
Primary risk factor	Hepatitis C in the general population	Chronic hepatitis B	Acute hepatitis B, chronic hepatitis C	Hepatitis A, B, and C
Group composition	31–59 years, 44.4% male	31–60 years, 46.4% male	31–56 years, 51.4% male	34–63 years, 100% male
Highest degree of education	33.3% college, 16.7% postgraduate	46.4% college, 64.3% postgraduate	37.1% college, 2.9% postgraduate	55% college, 20% postgraduate
Ethnicity	Mixed ethnicities	Mixed Asian ethnicities (58% foreign born)	African American	Mixed ethnicities
Moderator	Caucasian female	Asian male	African American female	Gay male