

# Sources and Accuracy of Information for Patients with Hepatitis C

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## Abstract

Favorable outcomes for patients with HCV depend on patients receiving accurate information about HCV and treatments. Effective patient communication consists of providers transmitting clear information and patients receiving and interpreting information accurately. Most patient communication research has focused on the former. The purpose of this study is to identify sources of patient information about HCV and treatment and examine accuracy. Data from 9 focus groups (N=48) were collected from patients recruited from large metropolitan public clinics and hospitals. Passages related to HCV (n=43) and treatment (n=50) were identified and coded by source and accuracy. Most (63%) information on HCV came from healthcare providers. In contrast, only 28% of treatment information came from providers. Accuracy of information received was 71%-89%. It is concerning that a substantial minority of disease process information and a majority of treatment information came from non-providers. It is also problematic that about ¼ of information was inaccurate. Focusing on communications from providers to clients to improve disease outcomes is overly simplistic.

## Keywords

Hepatitis C, treatment information, patient education, accuracy, qualitative

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## 1. Introduction

More than 5 million people in the US are living with hepatitis C virus (HCV) [1]. In the US, HCV is a leading cause of cirrhosis, hepatocellular carcinoma (HCC), and liver transplantation [5, 6, 9]. Because of shared risky behaviors and modes of transmission, nearly a third of those with human immunodeficiency virus (HIV) have HCV co-infection [14]. Because of recent pharmacologic advancements, pangenotypic direct-acting antiviral (DAAs) regimens are available for HCV and HCV/HIV co-infection with >95% virologic cure rates [12].

Despite highly favorable HCV cure rates and health benefits of HCV cures, most patients have not been treated [11]. In the continuum of HCV care (testing, linkage to care, HCV treatment, and HCV cure), there is a wide gap

between numbers of patients aware of their diagnosis and numbers of patients starting treatment—and a wider gap between those aware of their diagnosis and those cured [2, 4].

Among the barriers to HCV treatment noted in the literature [13], lack of knowledge about HCV and HCV treatment has emerged as a formidable barrier to HCV wellness and treatment initiation [3, 7, 8, 15]. In short, the majority of patients with HCV and HCV/HIV co-infection have knowledge deficits of HCV and HCV treatment, and those with knowledge deficits are less likely to modify their risky behaviors and prioritize and engage in HCV treatment.

A recent systematic literature review characterized general public and health care providers' knowledge of HCV and HCV treatment [13], but did not examine how patients received or assessed the accuracy of their information. Improving knowledge of HCV and HCV/HIV to achieve better disease outcomes requires dissemination of accurate information. Central to realizing this goal is identifying current sources of information and their relative accuracy. To date, no published studies exist that delineate sources of patients' information on HCV and HCV treatment and simultaneously address their accuracy. The purpose of this study was to provide an initial qualitative exploration addressing this knowledge gap in patients with HCV and HCV/HIV coinfection.

## 2. Methods

Participants of this study consisted of individuals taking part in one of 9 focus groups obtaining detailed information from persons with HCV or HCV/HIV co-infection about their experience of the illness and efforts to manage the treatment. Focus group data were collected from subjects recruited from public clinics and hospitals within a large metropolitan area. Four focus groups were conducted with HCV mono-infected ( $n=20$ ) and five with HCV/HIV co-infected ( $n=28$ ) patients. Inclusion criteria were an HCV diagnosis and no previous HCV pharmacotherapy. Basic demographic information for 77% of study participants was collected through brief surveys completed at the time of group participation. All methods for this study were approved by the University of Texas Southwestern Medical Center Institutional Review Board.

All focus groups were facilitated by an experienced focus group facilitator and an infectious disease specialist. Groups were conducted using nondirective methods, starting with a brief discussion of the group and its purpose. No questioning route or probes were established in advance. Groups lasted approximately 75 minutes. All groups were audiotaped, transcribed, and broken into passages. Passages were defined as an uninterrupted statement from a single individual. Further descriptions of the group methods are presented in a previous publication, to which readers are referred [10].

Based on the research question, passages were identified as related to the HCV Information or HCV Treatment by investigators with expertise in HCV and HCV treatment. HCV Information was defined to include passages related to diagnosis, mode of transmission, signs and symptoms, and disease progress. HCV treatment was defined to include passages related to medication regimen, side effects, length of treatment, and lifestyle change once identified, passages were coded by source (healthcare provider versus non-provider) and accuracy (accurate versus inaccurate/incomplete). Interrater reliability among coders (EWP, ER) was in the excellent range (all categories kappa  $<.90$ ). Accuracy was determined through consensus between co-authors (EWP, OTS). Where necessary, confirmation was determined through review of published peer-reviewed literature.

## 3. Results

The sample was approximately two-thirds male and two-thirds African-American. Median age was 50 years (range, 24-68). Coding yielded 93 coded passages, just under half ( $n=43$ ) coded as HCV Information and the remainder ( $n=50$ ) as Treatment. Table 1 presents findings according to source and accuracy. The majority of participants' information about the illness was reportedly received from healthcare providers, and in contrast, the majority of information received on treatment was from non-provider sources. Inaccuracy of information in all but one category ranged from 1/4 to almost 1/3.

Some participants reported that their providers had informed them only about nonspecific health measures and not about HCV specifically. One participant stated, "The [doctor] said my sodas, everything have to have no caffeine in it. I can't drink caffeine." Others reported inaccurate information: "The [doctor] told me not to take any pain medicine except Tylenol right now because I'm a woman." In contrast, accurate HCV information shared by these patients' providers included disease process, modes of transmission, and alcohol abstinence, for example: "My doctor over at the liver clinic said that it can be transferred via sex," "I've been told by physicians that the virus can actually stay on a toothbrush for days," and "My doctor told me that I can kiss [my grandkids] unless I have a cut."

**Table 1. Information by source and accuracy**

	<i>Overall</i>	<i>Not Completely Accurate</i>
<b>HCV information</b>		
By provider	27/43 (63%)	7/27 (26%)
By non-provider	16/43 (37%)	4/16 (25%)
<b>Treatment information</b>		
By provider	14/50 (28%)	4/14 (29%)
By non-provider	36/50 (72%)	4/36 (11%)

Participants received not completely accurate or frankly incorrect information about mode of transmission and disease process from sources of information outside their healthcare providers, such as: “[My family] wouldn’t let me kiss my grandbabies for a while,” “Someone was telling me the liver is one of the organs that can heal itself; is that a fact?” and “I was thinking there was a vaccine for C.” In comparison, accurate HCV information from non-healthcare provider sources included disease process and online sources of information, such as: “I’m hearing that [HCV] could go 20 years. I could pass away from something else, cancer, and perhaps never become an issue for me,” and “You can go to, I think it’s the National Liver Foundation; they have a website.”

Providers were reported as presenting patients with exaggerated requirements as well as only non-specific health measures, such as: “[My doctor] said [I will need to be] sober forever [because I have HCV] and I agree,” and “One doctor told me I couldn’t get on the treatment if I smoked, so I quit smoking.” In contrast, accurate healthcare provider treatment information covered topics of alcohol abstinence and medication side effects, such as: “My HIV doctor said [I must be] sober for a year. No drinking for a year [before treatment]” and “When the doctor explained about, you know, taking shots, you know? I don’t want to take shots and I don’t want to be sick.”

Some participants reported receiving incorrect information about HCV treatment from non-provider sources, such as: “Somebody told me you couldn’t take Tylenol [with treatment],” and “If I couldn’t get my treatment, my daughter started studying and I started buying it at \$30 a bottle. It was no good.” Accurate non-provider information represented the largest number of passages, including: “Oh, I’ve read horrible stuff, what’s his name, Liv Tyler’s father, Stephen Tyler; he described it...he went through 11 months of treatment and he said it was grueling,” “It did the same thing, [treatment] gets you sick; I remember reading it on the internet,” “I was in federal prison; a bunch of people in there went through the interferon; they said it made their test [go]...to zero,” “Don’t you lose your hair [from the treatment]?”,” and “I remember when that girl came on TV years ago and said that she was one of the first ones in Dallas to [get treatment], said that it’s not detectable anymore.”

#### 4. Discussion

The aim of this focus group study was to examine how patients get information about HCV and its treatment. Participants said they obtained most of their information about HCV illness from healthcare providers and about HCV treatment from non-healthcare providers. Overall, participants reported a concerning amount of inaccurate or not-completely-accurate information pertaining to both HCV and its treatment (approximately ¼) from all sources.

The finding that patients with HCV are almost twice as likely to report receiving HCV information from providers as from other sources may reflect normative processes for obtaining information about HCV. Logically, patients would obtain most of their knowledge about HCV illness from their primary healthcare providers who diagnosed HCV. Providers may also be the source of insufficient information, as primary care physicians presented much information about general health and minimal information specific to HCV. Knowledge received from hepatologists might be assumed to be more accurate. Additionally, obtaining information about treatment from non-providers may also reflect the delay between diagnosis and referral to a specialist for treatment.

Being informed of their diagnosis, patients might be expected to quickly seek information from as many sources as possible. This may be a function of the wait for a specialist appointment. Respondents reported accessing information through multiple additional sources, such as online searches, social media, and social supports.

A variety of possible explanations are possible for these patients’ incompletely accurate HCV information ascribed to healthcare providers. It is unclear whether the information actually provided by their providers or the patients’ understanding was the source of error. Some providers may lack current information given the rapidity of change in the HCV field. Some errors might arise from patients’ difficulties comprehending complex information

from authoritative sources including their healthcare providers. It is possible that the emotional impact of learning about one's HCV diagnosis prevented absorption and processing of information about HCV and its treatment. Also, ineffective provider-patient communication may contribute to misunderstanding. Possible explanations for incompletely accurate information attributed to non-healthcare provider sources may reflect inadequacies of those sources. The quality or accuracy of the information provided to these patients from the data generated by this study cannot be independently determined. Inaccuracies may reflect outdated information, unreliable sources of medical information, and/or anecdotal reports.

As an exploratory qualitative study, this research was not without limitations. Although the sample was purposive, including separate groups of individuals diagnosed with HCV and HCV/HIV coinfection, the findings are not necessarily generalizable to other individuals in other settings. These passages represent the participants' reported understanding and interpretation of rather than the actual content of the information they received. This study also had some significant strengths. Statements made in focus group settings allow opportunity for stimulation of discussion and opportunities for elaboration. The robust sample size for a qualitative study (48 participants in a total of 9 focus groups) and inclusion of clinically relevant subgroups (separate mono-infected HCV and comorbid HCV/HIV groups) generated rich opportunities for nuanced exploration.

This study's findings have implications for future research. Sources of information need to be specified in more detail, such as exact types of non-medical sources of information and the specific role of social media. Sources of error in provider-patient communication (inaccurate information provided versus inaccurate interpretation of it) need further examination. The sequential process of patients receiving medical and treatment information needs to be explored directly.

Findings from the present study reveal opportunities for improving patient understanding of HCV and its treatment with the hope of achieving better medical outcomes. Greater involvement of health educators with expertise in both HCV and patient communication might improve patients' likelihood of obtaining and maintaining useful, accurate information. Because these discussions revealed that patients receive most of their information from social sources, such as family, friends, and social media, educational interventions designed to engage and inform these sources may prove useful in achieving these goals. For example, leveraging of peers successfully involved in treatment as co-educators might represent a fruitful direction for developing effective education interventions.

## Authors' Contribution

The study conception is attributed to E. Whitney Pollio. Data analysis was performed by E. Whitney Pollio, Edward Randle and Omar T. Sims and the first draft of the manuscript was written by E. Whitney Pollio, Omar T. Sims and David E. Pollio and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

## Declarations

No funding was received to assist with the preparation of this manuscript. The authors have no relevant financial or non-financial interests to disclose. All methods for this study were approved by the University of Texas Southwestern Medical Center Institutional Review Board. Informed consent was obtained from all individual participants included in the study. Patients signed informed consent regarding publishing their data.

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