Between Facts and Voices:  
Medical and Lay Knowledge of the Spread of Hepatitis C  

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ABSTRACT  

Background: This research aims to better understand knowledge of the spread of hepatitis C virus (HCV). The medical perspective on how HCV is spread is clearly expressed in the literature. Most social scientific studies of health, illness, and health behavior assume that lay people’s knowledge can be adequately described as a matter of ignorance and misinformation judged against the paradigm of biomedical, scientific knowledge (Abraham et al 2000). However, research on lay people’s actual understanding and knowledge of how HCV is spread is scarce (Hopwood & Southgate 2003). The little research that has been conducted on lay knowledge of hepatitis C is a patchwork of research methods and perspectives. Studies of illness knowledge most often incorporate models from health psychology and epidemiology, whereby lay people’s knowledge is evaluated based upon its correspondence to accepted scientific standards (Brown 1995;). This study seeks to understand the everyday illness knowledge and beliefs of lay people. I investigate the degree to which such folk knowledge varies culturally in ways that cannot be explained solely by comparison with scientific knowledge. I examine patterns in the distribution of knowledge of the spread of hepatitis C (HCV) and investigate how social characteristics influence forms of knowledge.

Methods: This is a mixed methods study that examines both qualitative and quantitative data. Qualitative data (N=42) are from in-depth interviews with hepatitis C patients (Phase I of the NIH funded ARIMI Study, “Alcohol Reduction in Medical Illnesses: HCV as Prototype” NIH Grant #1 R01 AA13302-01A1). The in-depth interviews were transcribed and then coded using qualitative data analysis software. Quantitative data (N=3092) are from the CDC’s Behavioral Risk Factor Surveillance System (BRFSS) telephone survey. The survey data were analyzed with exploratory and confirmatory factor analysis, latent class analysis, and latent class analysis with covariates (Bollen 2002; Muthen 2004).

Results: The qualitative analysis found that respondents have a broad range of knowledge about how HCV can be spread. The respondents discuss many transmission vectors that were not present in the CDC survey. Just as scientists may argue with one another about hypotheses, theories and results, patients and individuals in their social network may argue about how HCV is spread. Among patients and lay people knowledge is negotiated and so are the actions associated with knowledge.
The quantitative analysis found three latent classes (three forms of knowledge of the spread of HCV). I characterize these three forms as follows (Figure 1): *HCV is Everywhere* (15.4%): HCV is easily contracted from many sources; *HCV is Nowhere* (54.9%): HCV is almost impossible to contract from any source; and *True Awareness of HCV* (29.7%): Knowing how HCV can and cannot be contracted. The likelihood of membership in each latent class (probability of having each particular form of knowledge) was estimated for each respondent based upon their responses to seven questions about how they thought HCV could be spread. The forms of knowledge are not randomly distributed across the population, but rather the likelihood of having a particular form of knowledge is associated with socioeconomic status, age, racial and ethnic background, marital status, perceived risk, and knowing someone with HCV.

**Figure 1: Distribution of Forms of Knowledge (Most Likely Latent Class)**

![Figure 1: Distribution of Forms of Knowledge (Most Likely Latent Class)](image)

**Conclusions:** In synthesizing the qualitative and quantitative results, I conclude that how we describe people’s knowledge can be in part a function of which questions we as researchers chose to ask and how we chose to examine the responses. Variation in lay people’s knowledge of the spread of HCV is culturally situated and cannot be viewed simply as part of a continuum of fidelity to biomedical and scientific evidence. I further conclude that the forms of knowledge of the spread of HCV are connected to social structure and social inequality.
Selected References


