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Hepatitis C and Philadelphia's Fire Fighters: A Union's Role in the Conceptualization of an Illness

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Hepatitis C and Philadelphia's Fire Fighters: A Union's Role in the Conceptualization of an Illness

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HEPATITIS C AND PHILADELPHIA'S FIRE FIGHTERS
A UNION'S ROLE IN THE
CONCEPTUALIZATION OF AN ILLNESS

By
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AN UNDERGRADUATE THESIS

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ABSTRACT

The purpose of this study is to demonstrate the role of a union in the conceptualization of hepatitis C by Philadelphia's fire fighters. I was interested in seeing how the union was able to fight for changes to help its members in a long battle with the city of Philadelphia. Hepatitis C was and continues to be an interest for this large group of people, but the discourses and knowledge surrounding the illness were centralized, emerging as the union's constructions. I hypothesize that the power of a collective group enabled the fire fighters both with and without hepatitis C to have a particular cultural model of hepatitis C. This model was one in which the people were agents and the disease was not biomedically defined, but given meaning through personal experiences and feelings.

In order to identify the ways in which the fire fighters thought of and about hepatitis C, I conducted an extensive mixed methods study. Questionnaires were developed and distributed to members of the fire fighter's union to capture the views of the fire fighters themselves. In addition, I reviewed and analyzed the portrayal of hepatitis C in the public sphere by the media, the union, the city of Philadelphia, and the state of Pennsylvania. I combined direct empirical research of personal experiences and feelings, with the information available to the public and the fire fighters to determine the model the fire fighters held.

The union invested this group with a sense of power and agency and successfully enacted changes on their members' behalves. I suggest that collective action and support from a central location working to personalize a problem were essential to the union's success. The fire fighters will now be covered by their worker compensation for this potentially life threatening disease. In the eyes of the union, hepatitis C is not just a disease with which one is diagnosed. The cultural model of hepatitis C empowered the fire fighters to contest the norms and beliefs of the United States' capitalist culture surrounding disease, equal access to health care, responsibility, and economic gains.
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INTRODUCTION

December 6, 2000 Philadelphia paramedic Lt. Mary Kohler* entered City Hall prepared to stay until Mayor John Street recognized hepatitis C as a work related injury for first responders. As she sat on the cold, hard floor of the ominous building, Kohler was about to run out of sick time. She suffered from “agonizing joint pain, chronic fatigue, and tremors” (Loviglio 2000). She was weak and had to move to the privacy of the bathroom everyday to administer her medication for hepatitis C. She is one of the more than 100 Philadelphia fire fighters and paramedics diagnosed with hepatitis C, a viral infection that can lead to chronic liver disease. Kohler’s plea was one for recognition and a raising awareness. She and the other fire fighters of Philadelphia wanted the city to take responsibility to help the people on whom it depended to serve others. Mary Kohler spent 15 days in City Hall fighting for this cause. Her coworkers came out in support, but were not allowed into the building, kept at bay by the police. She wanted the city to pay for the treatment of this disease that she and other firefighters say they were exposed to in the line of duty.

How did this woman have the courage to contest the city of Philadelphia? Why was the city not listening to the concerns of its employees? How was hepatitis C affecting the lives of the infected fire fighters and paramedics? Where and from who were these people getting support? What is the cultural context in which all of this emerged? These were just some of the questions that came to mind when I first learned about the situation of Philadelphia’s fire fighters. This was a group with intimate contact with hepatitis C, which is still for most people a relatively unknown disease.

* Mary Kohler has come forward in the public and in many media sources as having hepatitis C. All responses to questionnaires for this study were anonymous and confidential because of the sensitive nature of this issue.
Working for Yale’s Emerging Infections Program, Liver Study Unit for the past two summers, I became interested in hepatitis C. The New Haven County Liver Study (NHCLS) is the first prospective population based study that identifies patients who present with chronic liver disease (CLD) for the first time. The epidemiological approach to chronic liver disease (CLD) interested me a great deal. The initial statistical analyses from the New Haven County Liver Study (NHCLS) looking at changes in emotional, mental, and physical health in people with hepatitis C were the impetus for this study. However, I wanted to learn more about individual experiences and perceptions of a disease as an illness and felt that the methodologies of anthropology were best suited to undertake this project.

I decided to specifically concentrate on hepatitis C because of the emerging literature suggesting that the impact hepatitis C has on patients is much greater than for other causes of CLD. Hepatitis C interested me as an emerging infectious disease and a disease for which the knowledge surrounding it not only in the public sphere, but also in the medical community is currently limited, and undergoing a state of growth.

In this extensive mixed methods study, I have attempted to capture the way in which hepatitis C was constructed and conceptualized by the fire fighters. I have relied upon the methodology of critical medical anthropology, epidemiology, and public interest anthropology to capture the complex nature of this issue. I have posited my own empirical research in combination with a review and analysis of the discourses in media documents, union information, and the responses of the city and the state. This research helps to illuminate the real impact of this disease on the lives of those people closely related to it, in addition to finding the way in which one’s cultural context affects the way in one perceives a disease as an illness.
Focusing on the Philadelphia fire fighters, it emerged that the issue of hepatitis C was framed through and by Philadelphia’s Local 22 Union of Fire Fighters. I came to see that the fire fighters are a unique group because of the role of the union. The fire fighters united within a union that was setting the dominant discourse and increasing or influencing the knowledge these people had about the disease and its effects. I have attempted to see how this information and knowledge was disseminated and constructed within the local union, the International Association of Fire Fighters, and at the level of personal everyday lived experience.

The literature review and intellectual framework investigates the knowledge of hepatitis C in the biomedical community, as well as detailing the ways in which medical anthropology, cognitive anthropology, epidemiology, psychological anthropology, and public interest anthropology are useful in this study. The construction of disease and definitions of health must be seen in a cultural context to fully understand the way in which disease is not only a biological category, but also a social and cultural one. Structurally, I position biomedicine within the capitalist economy of the United States to see the ways in which power has functioned in this societal institution and been the defining force in people’s conceptualizations of disease. I also examine the role of the fire fighters as civil servants employed by a societal institution.

Additionally, I address the way in which the union was able to construct hepatitis C as an illness and work for change. Which set of knowledge; the union’s, the city’s, the state’s, biomedicine’s, has more authority and legitimacy? The level of authority of each of these groups played an important role in the way in which the disease was constructed in the minds of the fire fighters who are hepatitis C positive and those who are being warned of its dangers. I have seen that the cultural models held by the union, as a collective, and by the members, as individuals,
constructed this disease, as an illness that could be overcome by actively working against the institutional and cultural norms.

**Literature Review and Intellectual Framework**

**Hepatitis C – Biomedical and Epidemiological Background**

Hepatitis C is the leading cause of chronic liver disease (CLD) in the United States (Alter et al. 1999:556). It is estimated that approximately 3% of the world’s population is infected with the hepatitis C virus (HCV). Hepatitis C is also the most common chronic blood borne infection in the United States (Alter, et al. 1999:560). Approximately 100 million people worldwide are infected with HCV and of this, 4 million are in the United States (Figure 1) (Ware, et al. 1999:550). Between 8,000 and 10,000 people with chronic HCV die each year (Larson and Carithers 2001:114). Hepatitis C was successfully classified and cloned in 1989, making it a relatively recently discovered infectious disease (Larson and Carithers 2001:111).

HCV is classified in the family of Flaviviridae and in the genus Hepacivirs (Larson and Carithers 2001:111). It is a single stranded RNA virus, which encodes for a capsid protein, two envelope proteins, and at least six non-structural proteins. The RNA sequence can vary up to 35% and the virus can be classified into six major genotypes (Larson and Carithers 2001:111). HCV genotype is one of the “strongest clinical predictors of response to antiviral therapy” (Larson and Carithers 2001:111). Research has indicated that once HCV infection is established,
the virus undergoes mutation in the body. Many individual virus particles are then produced, each differing by at least one site in the RNA sequence (Larson and Carithers 2001:111).

An acute infection of HCV has an incubation period of 15-150 days. Those infected are usually asymptomatic or may develop mild flu like symptoms (Larson and Carithers 2001:113). Of those people with HCV infection, approximately 70% develop chronic infections (Ware, et al. 1999:550), where the virus is present in the bloodstream for more than six months. Symptoms may include, fatigue, pruritus, abdominal pain, and nausea. Unlike with HIV, viral titers of HCV do not correspond to the activity of the hepatitis (Larson and Carithers 2001:113). HCV most often advances to the chronic condition, because of its ability to evade the immune system of the host. The progression of the disease also varies depending on the person and the particular genotype of the virus.

Some patients may have chronic hepatitis C for 50 years and never develop any liver damage, while others can develop cirrhosis of the liver and hepatocellular carcinoma in 10 to 15 years (Larson and Carithers 2001:114). About 20% of people with chronic HCV develop cirrhosis of liver in 20 years, in which the tissue dies and becomes fibrous unable to perform its normal functions (Larson and Carithers 2001:114). The average patient is not diagnosed until 15 years after contraction of the disease and develops evidence of cirrhosis or progresses to hepatocellular carcinoma 25 to 30 years after infection (Larson and Carithers 2001:114).

Diagnostic testing for HCV is done with an enzyme linked immunoassay (ELISA). This test can detect antibodies to the virus in over 97% of infected people (Larson and Carithers 2001:112). However, this technique is unable to distinguish between acute, chronic, and resolved infections. Just 15 weeks after exposure, antibodies are measurable in over 80% of infected people. After five months, this rises to 90% and after 6 months jumps to 97% (Larson
Because of the chance of false positives, an alternate diagnostic method is used to confirm infection. The recombinant immunoblot assays (RIBA) directly measure the amount of circulating HCV RNA to prove seropositivity (Larson and Carithers 2001:112).

**Determining Prevalence in the United States**

The percentage of the United States population infected with HCV was first analyzed through a study samples from volunteer blood donors. This however, was not an accurate reflection of the prevalence in the general population as the group was self-selected to donate blood (Alter, et al. 1999:556). To gain a better representation of the prevalence, serum samples were collected from participants in the third National Health and Nutrition Examination Survey (Alter, et al. 1999:556). Of the 40,000 people involved in the survey, 21,241 were tested and a prevalence rate of 1.8% was found (Alter, et al. 1999:557). This study represents the best estimate of the prevalence of HCV in non-institutionalized populations since its discovery in 1989.

Within this cohort, HCV was higher among non-Hispanic blacks and males. In addition, 65% of all HCV positive persons were 30-49 years old. Therefore the burden of infection, defined as the number people with and being treated for hepatitis C, should increase in the next 10 to 20 years as most people infected are currently under 50 (Alter, et al. 1999:562). In the next two decades, the majority of those people infected before there was knowledge of the disease, will reach the age at which many more liver complications occur.
City of Philadelphia Department of Public Health Statistics

City and state public health departments have lists of reportable diseases and collect population based data on these diseases over time. Hepatitis C is one of the communicable reportable diseases in Philadelphia, meaning that any laboratory must report those patients with serologic evidence of hepatitis C to the City Department of Public Health. Philadelphia's own Division of Disease Control established a registry in 1998 of those people with hepatitis C to "facilitate counseling, education, and follow-up of infected persons" (City of Philadelphia Department of Public Health 2000:8). In 2000, 1,330 new patients were added to the registry. However, this number may not represent all true infections, for the reports from labs often do not include confirmatory test results.

Looking at the number of reported serologies in Philadelphia from 1998-2000 by age group and gender, several trends emerge. In these three years, there were 6,743 reports of serologic evidence for HCV infection (Figure 2). Both men and women aged 30-59 have the highest rates of HCV infection with 1,632 cases in women and 4,017 cases in men. Within this age group, men aged 40-49 have the highest number of reported cases at 2,210. Additionally, in every age group except those people over seventy, the number of infections in men is higher than in women. (City of Philadelphia Department of Public Health 2000:8)

New Haven County Liver Study -- HCV versus Non-HCV Participants

Questions in the NHCLS were asked in a routine patient interview, once people had been enrolled in the study through identification in gastroenterology clinics in New Haven, Connecticut. The questions pertaining to the information I was most interested in were self-assessment of one's health over a 30-day period. From analysis of unpublished data, respondents
with hepatitis C report worse health than respondents with non-HCV CLD (Figure 3). Running a t-test on the data for 440 patients, those with hepatitis C 271 or 61.59% of participants (Figure 3), report a significantly greater number of days of ill health. When asked about physical health, those participants with hepatitis C say their health is not good an average of 9.26 days, with a p value of 0.0076 and those without hepatitis C report their physical health not being good an average of 6.23 days, with a p value of 0.0085 (Table 1). Similar results were found for mental health, which included stress, depression, and problems with emotions over the past 30 days. For those people with hepatitis C, the average number of days of ill mental health is 10.62, p value of 0.0000, and for those without, the average is 5.88 days, with a p value of 0.0001. Participants were also asked to assess the number of days during which poor mental or physical health kept them from doing their usual activities, including self-care, work, and recreation. Those people with hepatitis C on average report that poor health keeps them from their usual activities 6.47 days, with a p value of 0.0161, in the past 30 days and those without hepatitis C report an average of 4.21 days with a p value of 0.0191. (St. Louis 2002)

Review of Studies Addressing the Impact of Hepatitis C

Other infectious agents, behaviors, drug interactions, and immune disorders can cause chronic liver disease resulting in cirrhosis, hepatocellular carcinoma, and liver failure. However, those people infected with HCV occupy an interesting position. Many studies have shown that HCV affects people much more negatively and adversely than other causes of CLD. When matched with the general populations, survival in a cohort of patients with chronic HCV infection was markedly reduced (Niederau et al. 1998:1689). In those patients with cirrhosis from their HCV, there was also increased mortality by almost fourfold (Niederau et al.)
It was found that other factors also contributed to decreased survival rates. These included development of cirrhosis, excessive alcohol consumption, which would aggravate the already abnormal condition of the liver, a history of intravenous drug use, and old age (Niederau et al. 1998:1689).

The “general perception that hepatitis C is an asymptomatic disease with a benign natural history” has implicitly stated that it has little effect on the quality of life (Carithers et al. 1996:75). However, when assessments have been done to determine the impact on quality of life there have been significant results to counter this viewpoint. Using the sickness impact profile, HCV patients scored lower in all categories, except eating (Carithers et al. 1996:76). Since this profile lacked disease specific questions, another questionnaire, the short form health survey, was also used. This measures physical functioning, physical bodily pain, general health, perception, vitality, social function, role - emotional, and general mental health (Carithers et al. 1996:77). When compared to the general population, the HCV cohort scored lower in all eight categories. Compared to other studies involving chronic diseases, HCV responders were most closely linked to people with type II diabetes. These are both chronic diseases that affect younger people and influence the ways in which patients feel about themselves and their functioning on a daily basis (Carithers et al. 1996:79).

In fact, the very diagnosis of HCV has been shown to have an impact on people’s self-reported quality of life. In a study conducted by Rodgers et al., scores on quality of life scales for 34 chronically infected individuals were much lower than those of healthy controls (1999:1299). There are “potentially adverse consequences of a diagnosis of HCV per se unrelated to objective measure of pathogenicity” (Rodgers et al. 1999:1301). It was found that most patients reported “disabling chronic fatigue and a reduced sense of well-being” (Rodgers et
al. 1999:1299). Compared to healthy controls those aware of their seropositivity for HCV had reduced scores in 7 of the 8 scales used to measure quality of life. There was “subjective perception of extremely poor physical health and mental health,” along with limitation of daily exercise, bodily pain, poor social functioning and emotional problems” (Rodgers et al. 1999:1300).

This study also included people unaware of their seropositivity for HCV, the fact that this group also reported symptoms of fatigue may indicate that such symptoms of poor physical and mental health may be in part physiological and not only psychological (Rodgers et al. 1999:1301). However, the overall reduction in quality of life scores for this cohort of HCV positive people, is also attributed to “partially an effect of ‘labeling’ by which diagnosis of a chronic disease per se affects subjective psychological well being” (Rodgers et al. 1999:1301). Rodgers et al. did not compare the impact of hepatitis C to the impact of other chronic illnesses.

Using a population of 324 patients who had been on interferon treatment for HCV, but relapsed, Ware et al., analyzed the impact of HCV on quality of life (1999). Matching results with studies done on another chronic disease, hypertension, those people with HCV reported significantly more impairment in vitality, social functioning, and mental health (Ware et al. 1999:554). The nonspecific complaints of this group included, fatigue, irritability, anorexia, muscles ache, headache, and abdominal discomfort. These impacted the way in which one functioned on a day to day basis, perception of psychological well-being, and health (Ware et al. 1999:550).

After having undergone treatment and having a consequent relapse, the percentage of this group that was discouraged by hepatitis C rose from 17% to 34% (Ware et al. 1999:553). There was a similar increase, from 24% to 50%, in those people reporting they were worried about their
hepatitis C after a failed course of treatment (Ware et al. 1999:554). This study involved patients from many different countries and the results for those people from the United States varied slightly from other respondents. In five of the 8 domains examined by the quality of life questionnaires, the United States respondents had lower results (Ware et al. 1999:552). These areas were in role-physical, general health, vitality, physical functioning and social functioning.

Reduced quality of life was also reported by Forton et al, when looking at a group of 220 people with chronic hepatitis C (2002, in press). Often complaints of nonspecific symptoms are attributed to the HCV infection and one of these is clinically significant depression (Forton et al. 2002, in press). Anxieties regarding diagnosis, prognosis, and treatment are commonplace. Because perception of well being has been shown to improve with anti-viral therapy, the symptoms may at least be in part due the disease process. Of the 220 patients, 35% reported emotional distress and this was not linked to a history of IV drugs or alcohol use. Such a prevalence of psychiatric symptoms, more than twice what is expected for a chronic illness, may in fact be a direct viral mechanism, which triggers neuronal dysfunction (Forton 2002, in press).

Fontana et al. studied patients at hepatology clinics at the University of Michigan (2002, in press). Psychiatric and emotional problems are higher in chronic hepatitis C populations than in the general public. Of the participants from the clinics, 71% had psychiatric or medical co-morbidities (Fontana et al. 2002, in press). Between 22% and 40% of the participants were experiencing emotional distress (Fontana et al. 2002, in press). Within this group, it was shown that married people had lower stress levels and those with a higher education level expressed a better understanding of the disease (Fontana et al. 2002, in press). However, it was reported by 41% of the participants that they did not know the impact that chronic hepatitis C had on their health (Fontana et al. 2002, in press). Feelings of depression, somatization and anxiety are high
among many people with chronic illness. Furthermore, Fontana et al. suggest that the psychoticism is a reflection of feelings of alienation that arise from the fact the HCV is an infectious disease (Fontana et al. 2002, in press).

These studies position hepatitis C as impacting people at many levels including physical, emotional, and psychological. These studies point to the construction of hepatitis C within a cultural and social context that has not yet fully understood or explored. Some aspects of this disease may in fact be biological. However, this may be a function of translating factors that are socially and culturally context laden into scientific terms, which in a sense can make the problems seem more solvable. All these studies point toward hepatitis C having a negative impact on physical, mental or emotional health. However, there is still the question of what are the ultimate causes of these conditions and how are some conditions specific to one’s cultural and social environment. There is still a lack of authoritative information regarding hepatitis C and other areas of research within the social sciences are perhaps better suited to broach these topics.

Construction of Hepatitis C in Society – An Anthropological Approach

Very little anthropological literature exists, addressing hepatitis C. Krug (1995) examines the way in which hepatitis C is constructed and understood in Australia which has a prevalence rate between one and four percent. Krug hopes to develop “strategies for education and invention in the defining of social problems” (Krug 1995:299). With hepatitis C, it is important to “determine the conditions of privilege, of power, and of voice in giving meaning to this condition” (Krug 1995:300). Krug acknowledges that his methodology and process is self-consciously political, for he is working to find ways to intervene and have others intervene in the
social practice of meaning (1995:301). His anthropological approach locates the “intersection of personal problems and public issues” (Krug 1995:301). With hepatitis C only having been discovered and named in 1989, medicine and public health have yet to establish a definitive meaning of hepatitis C. Therefore the “discourses defining and surrounding HCV are themselves unstable and relatively free-floating” (Krug 1995:302).

For people with HCV, there exists an absence in the discursive domain, however the “medical and social ramifications necessitate a construction of it into meaningful narratives, stories, beliefs, and plans for action” (Krug 1995:303). People who have contracted the disease “have been told that something important about them and their lives have changed, but no one can say what exactly is different” (Krug 1995:304). In viewing hepatitis C as only a disease, one misses the social discourses and manifestations of it in people’s lives (Krug 1995:304). Often with disease, the medical domain dominates not only in medical settings, but elsewhere and this is the discourse, which comes to structure and enter the lives of the people with the disease. This leads to a medicalization of the self (Krug 1995:304). People with the disease are constructed as patients by the biomedical discourse, and people continue to use this identity to seek a “definition of their diseased lives” (Krug 1995:307) that often does not have personal significance.

Discourses and the power they hold are extremely important. Krug found that one of the most frequently stated concerns of people with HCV was that the “condition is serious and it not recognized as such by those in power” (Krug 1995:305). Often, “medical discourse is the only one with the power of ‘truth’ in their social interactions” (Krug 1995:315). Therefore the “process of living is transformed and rewritten into a medical ‘case’” (Krug 1995:315). The individual particulars of the person are ignored or masked by the discourse of the disease as a
pathological entity. The personal experiences of the person are completely divorced from the medical model. Those people afflicted with disease may end up talking like doctors because of the overarching authority for the biomedical model of the disease (Krug 1995:316).

A positive diagnosis comes with an “almost inevitable desire for information” (Krug 1995:312). However, the only discourses, which exist to explain the disease are medical and scientific. There needs to be narrative that can restore meaning for the individuals. Krug states there is “no realistically achievable amount of information [that] will allow most people to challenge the medical discourse” (Krug 1995:318). Anthropology is one way in which the presence of this power can be acknowledged and analyzed. With the recognition of the role of power, comes the ability to reposition oneself in the structures of power and restore continuity to discourses surrounding HCV, so that models other than those disseminated by biomedicine can help people to find personal meaning of this disease (Krug 1995:319).

Variables and Stigmas

The initial prevalence study by Alter et al., also tried to determine the cofactors for HCV infection. It did not show an association with infection and employment in health related occupations, surgery with blood transfusions, or dental visits (1999:557). With continued research it has been shown that especially in industrialized countries, HCV is “hyperendemic” among intravenous drug users versus a control group in which 1% of participants had ever injected illicit drugs, 51% of HCV participants had used intravenous drugs (Murray et al 2000:756). This same study revealed that there was an odds ratio of 3.2 of contracting HCV from being stuck with an HCV positive needle. With weaker, but significant odds ratios of 1.7,
surgery, getting sutures, and nonspecific occupational blood exposure were other methods of contraction (Murray et al 2000:758).

Data from the NHCLS population based study of CLD demonstrate the variables that are significant for those participants with hepatitis C as compared to people with CLD, without hepatitis C. Looking at the HCV participants versus those without HCV, the variables associated with HCV are a greater percentage of people with an income below $50,000, no education beyond the high school level, heavy alcohol use, any history of past non-intravenous drug use, and any history of past intravenous drug use (Figure 5 and Figure 6). This information is important for future research, because the data reveal that at least in this study, which is demographically representative of the U.S. population as a whole, there are certain factors that may be present to a greater extent in a group with hepatitis C as a cause of CLD, as opposed to a group with other etiological causes of CLD. (St. Louis 2002)

The stigmas in society surrounding the use of intravenous illicit drugs create a medium in which most people will not admit to ever having used drugs in this manner. Also, diseases then associated with such behavior, become specific to that population in many people’s eyes, and the possibility of other routes of infection are often masked. People with HCV, may not have contracted the virus from using drugs, but they may feel ashamed in social settings to admit that they have HCV for fear they will inevitably be associated with the behavior most often linked to the disease.

From a public health perspective, if people do not admit the route of exposure, it creates a difficult task in truly determining rates of transmission and contraction risks. However, the power of the stigmas against admitting such a practice, acts on people and they will answer in a socially acceptable manner. Drug use especially, may have been long ago in a person’s past.
There is then the struggle to “reconcile their current self-conception with the selves associated with their earlier behavior, selves that they may have abandoned long ago” (Krug 1995:310). With the initial discovery of HIV there were many stigmas associated with the disease and HCV can be seen in a similar light in many respects. There does not exist a construction in the public domain of the HCV sufferer, so there must be an attempt made to educate the public about this disease (Krug 1995:309). In Australia it was found that among politicians and community and public health bureaucrats, the perception is that the current HCV epidemic was predominantly among intravenous drug users (Crofts and Louie 1997:88).

Another study in Australia conceived of HCV as the “next plague” because of the stigmatization and discrimination faced by people with the disease (Crofts and Louie 1997). Actions to remedy discrimination have yet to take place even though up to 80% of those people found to be HCV positive have a lasting infection (Crofts and Louie 1997:87). In Australia, testing became available in 1990, yet there have not been guidelines established related to counseling surrounding testing and diagnosis. Likewise, education to make practitioners and the public aware of the meaning of the tests results is absent (Crofts and Louie 1997:88).

When asked about problematic settings concerning their hepatitis, it was found respondents had incidents in a wide range of interactions. People were most often met with either rigorous infection control measures or total neglect. Forty-six percent of incidents took place in health care settings, 22% in domestic situations, 20% at work, and 10% in recreation, social security, day care, funeral or prison settings (Crofts and Louie 1997:89). Problems at work most often led to demotion, transfer, termination, or exclusion by co-workers. Eighty three percent of these incidents were also reported to have substantial personal implications with 63%
affecting personal relationships, 61% having social implications, 44% having occupational implications and 37% reporting financial implication (Crofts and Louie 1997:92).

These studies have shown that the stigmatization faced by people with HCV directly affects personal interactions and social situations. A disease is not solely diagnosed, it is ever present and has repercussions at all levels not only for the individual with the disease, but also for the society in which that person lives. There is the “urgent need to present the major social harms which can follow HCV diagnosis and disclosure” (Crofts and Louie 1997:93).

Medical Anthropology

Medical anthropology is a subdiscipline of anthropology, which analyzes diseases, illnesses, and healing systems as part of culture. “From the anthropological perspective, diseases can not be explained as purely ‘things in themselves’; they must be analyzed and understood within a human context...” (Brown, Inhorn & Smith 1996:183). Culture provides, “a theoretical system for understanding – and attempting to manipulate through medicine - the diseases that cause human suffering and death” (Inhorn and Brown 1997:54). Focusing on mental processes, culture emerges as idea systems and systems of symbolic meaning (Pelto and Pelto 1996:301). Studying the interrelationships between health and other spheres such as the economy, the environment, politics, and cultural norms and beliefs can help one to better understand diseases as more than biological entities. “Medical anthropology speaks of, and speaks from within, the complex intersection of social institutions and the bodies and selves of individuals” (Rhodes 1996:179)

Medical anthropology first established the difference between disease and illness. Diseases are considered to be the clinical entities, with “pathological underpinnings” (Inhorn and
Illnesses are then what are more closely linked to patient's perceptions and behaviors and intimately tied to one's culture (Inhorn and Brown 1997:32). Foucault asserts there is "no external position of certainty" and an anthropological worldview holds this at its forefront, analyzing how something is shaped by the historical and social contexts in which it arose and exists (Singer and Baer 1995:59). In trying to gain an understanding of the role of culture in health and disease, one must account for cultural particulars along with individual differences.

**Infectious Diseases, Epidemiology and Anthropology**

When addressing the issue of an infectious disease in the United States, it is also important to examine the role of public health and epidemiology. In applying techniques from these fields along with anthropology, an interdisciplinary approach to disease can help yield the best picture of the intricate nature of the situation. Combining these traditions, any human disease or disorder is positioned as the "result of many factors within what may be described as a causal web" often focusing on behavioral determinants (Dunn and Janes 1986:3). Epidemiology is a behavioral science addressing health-related behavior and disease (Dunn and Janes 1986:3). Medical anthropology addresses the same behaviors and analyzes the same disease, but focuses on the social and cultural contexts in which behaviors arise (Dunn and Janes 1986:3).

Epidemiology focuses on large population aggregates, based on boundaries pertaining to geography or demography (Dunn and Janes 1986:7). The quantitative nature of collecting data in the public health field is known for its greater validity, however qualitative techniques employed by disciplines like anthropology are also useful. When accompanied "by sound sampling methods and procedures for limiting observer bias" qualitative data can be very reliable.
In essence, what anthropology can do for epidemiology, which addresses populations based causes for disease, is "amplify the behavioral dimension of a causal assemblage" (Dunn and Janes 1986:28). Anthropology and more specifically medical anthropology, stands in the position to augment epidemiological data about a particular disease with cultural specifics and the understandings and conceptualizations people have of disease, illness, and health.

Hepatitis C is just one of many infectious diseases that afflict human beings. Infectious diseases are the major cause of death worldwide (Inhorn and Brown 1997:3). With "anthropologists, as professional observers and interpreters of human behavior in its social and cultural context," infectious diseases are a logical area of study for many diseases have arisen in human populations as a result of certain behaviors (Inhorn and Brown 1997:5). "Culture manufactures disease" as societies are constantly changing ecologically increasing and decreasing the risk for diseases (Inhorn and Brown 1997:54). Human populations can be seen as adapting to infectious diseases at the "levels of both genes and culture" (Inhorn and Brown 1997:31). For this reason, disease within medical anthropology is often seen as the "prime mover in cultural transformation" for there are direct responses in health when there are social, economic, political, and psychological disruptions (Inhorn and Brown 1997:31).

**Perspectives in Medical Anthropology**

Several perspectives have been developed in medical anthropology to address the relationships among health, disease, behaviors, and culture. One of these is the ecological perspective which "views health and disease as reflections of ecological relationships within a population, between neighboring populations, and among life forms and physical components of
a habitat” (McElroy and Townsend 1985:2). This view holds humans as both biological and cultural creatures with health as a measure of the ability to adapt to the environment (McElroy and Townsend 1985:7). Culture, in this perspective, becomes the strategies for survival developed as a result of the pressures of natural selection. This Darwinian approach to medical anthropology sees the components of culture as technology, ideology, and social organization, with individual adaptations resulting from psychological concepts (McElroy and Townsend 1985:104). This conception is useful in viewing humans as connected to the environment and not removed from the struggle for survival they are engaged in with other living creatures. However, the development of what is called political ecology is much more applicable to the situation of many more current diseases in industrialized countries.

Turshen’s use of the political ecology perspective of disease arose out of her analysis of other existing models (Inhorn and Brown 1997:40). These models were inadequate because they were failing to consider the real and ultimate causes of disease (Inhorn and Brown 1997:40). When medicine is exempt from a cultural analysis, there arises a dichotomy between culture and nature (Lock and Scheper-Hughes 1996:43). This new Marxist conception insisted that poor health had to be seen as influenced by the economic, social, and political conditions of a culture (Inhorn and Brown 1997:40). Morsy points to yet another shift in perspective, termed political economy which considers the global structural relations, but continues to examine the “cultural, social and experiential particularities of sickness and healing” (Morsy 1996:27).

The political economy approach to medical anthropology asserts that not only medical knowledge, but also anthropological knowledge are “socially informed products of particular historical and cultural contexts” (Morsy 1996:25). Expanding on these new views, many other medical anthropologists began to analyze more thoroughly all aspects of social existence when
looking at disease. This tradition became known as critical medical anthropology (CMA). There
was now the perception that the origins of suffering “must be analyzed from all levels” (Inhorn
and Brown 1997:54). It was also essential to understand the many levels of analysis of power
relationships. Brown notes that, “political power and access to resources are important processes
and determinants of culture change, and it becomes important to answer the question of who
benefits from a particular change – and who loses” (1997:123). CMA emphasizes the
“importance of political and economic forces, including the exercise of power, in shaping health,
disease, illness experience, and health care” (Singer and Baer 1995:5).

CMA rests on the work of Marx and Gramsci in seeing that “dominant institutions and
their understandings of reality tend to legitimize, rationalize, and reproduce the dominant
relations of society” (Singer and Baer 1995:5). Throughout history and across cultures, it has
been noted that the dominant ideas and common sense notions are “disproportionately from
those of the dominant class” (Singer and Baer 1995:60). Specifically looking at Western
cultures and the traditions of biomedicine, CMA positions medicine as the “unintended agent of
capitalist hegemony and a tag-along handmaiden of global imperialism” (Singer and Baer
1995:5). The institution of biomedicine itself is seen as functioning to maintain social
inequalities (Inhorn and Brown 1997:54).

**Cognitive and Psychological Anthropology**

To discover the way in which people at risk for hepatitis C or those actually diagnosed
with hepatitis C perceive the disease, I decided to look to both cognitive anthropology and
psychological anthropology. Bock, contends that “all anthropology is psychological” and in a
certain sense the incorporation of the levels of analysis of perception, motivation, cognition, and
learning, place most studies within the stated goals of psychology (1999:1). Within this context, the individual's self-awareness and personality is considered in addition to the overarching environment of one's culture.

Goodenough's definition of culture is often used in this sub-discipline, as "that which needs to be known in order to operate reasonably efficiently in a specific human environment" (Bloch 1998:4). Applying this approach to health and illness, culture is positioned as a resource for making sense of a stressful event, such as a threat to well-being (Price 1987:42). Culture can then be thought of as the "behavioral and interpretative 'software' that people use to organize their experience and make them meaningful" (Brown 1997:123). This software gives rise to what can be categorized as habitual behaviors and common sense ideas and values. In anthropology, a definition of culture also incorporates the notion of motion and changes, for the "interdependent and patterned systems" are never static (Brown 1997:123). As Malinowski said, anthropology hopes to "to grasp the native's point of view, his relation to life, to realize his vision of the world" (Bock 1991:192). To attempt this, one cannot ignore the mental aspects of one's world.

Likewise, cognitive anthropology works to discover "how different peoples organize and use their cultures – attempt to understand the organizing principles underlying behavior" (Tyler 1969:3). One is not as concerned with the material phenomena, as much as the way in which those things are then organized in the mind. In looking for meanings, "...the stream of consciousness which we experience has its foundation in abstract conceptual models of the world" (Basso and Selby 1976:155). The "same material phenomena may be present, but subjectively perceived and organized differently" (Tyler 1969:4). Eliciting the categories people use to give meaning to experiences and objects is a central feature of this approach. "To
understand why people do what they do – have to understand the cultural constructs by which they interpret the world” (Strauss 1992:4). Concepts of society and culture can not be thought of as simple linear models, but instead “complex and highly integrated networks” to understand one’s lived in world (Bloch 1998:25). Society’s reality is full of meanings and “is built up out of concepts and terms that already contain...propositions about our needs, motives, and desires and the way we respond to the world” (Shweder 1992:54).

**Cultural Models**

Cultural models are one way to elucidate the inner workings of the mind in relation to cultural context. Behind this theory is the basic premise that the most important human processes are meaning construction and information processing (Shore 1996:7). There is a constant, active construction by people to understand experiences with “the help of cultural resources” (Shore 1996:7). Shore describes the theory of cultural models as “an ethnographic conception of mind, a notion of brain dependent for its functioning on a range of extrinsically derived models” (1996:10). This model hopefully bypasses the debate for a psychic unity and institutes a “cognitive view of culture” and “cultural view of mind” (Shore 1996:39). This places the locus of culture in both the psychological and the social arenas(Shore 1996:51).

Underlying these models are what D’Andrade describes as schemas; “a conceptual structure which makes possible the identification of objects and events” (1992:28). These can instigate action and see motivation as a connection between action and culture. It is important to note that the basic elements of cultural models will be “lexically encoded and used frequently by people in ordinary conversation” (D’Andrade 1992:34). However, when someone is asked to describe how one reasons and comes to a decision, it is difficult to put such a thing into words.
What often emerges are post-hoc rationalizations, so that one retrospectively provides explanations which may not have been exactly what was being cognized at the time (Bloch 1998:23).

Cultural models exist both in the world and in the minds of members of communities. Experiences will have different models depending on the role of the person in the situation. The cultural model of a doctor’s visit will be different from patient to patient and these will vary from the models of the same situation held by the doctor. “Cultural models are socially distributed in that not all members of a community will share all the same models or will have the same variant of a model” (Shore 1996:312). Cultural models are useful for determining how people perceive and come to react to situations in the same way.

Critical Medical Anthropology and Biomedicine

Biomedicine is positioned and established on culturally limiting assumptions of causation and disease; and it follows that all reality can be seen as socially constructed (Inhorn and Brown 1997:54). Diseases are only the proximate causes of suffering. CMA asserts that biomedicine fails to recognize how “ultimate etiologies involve political and economic inequality” (Inhorn and Brown 1997:54). CMA hopes to gain a “holistic understanding of the causes of sickness, the classist, racist, and sexist characteristics of biomedicine as a hegemonic system” (Singer and Baer 1995:6). This alternate role of biomedicine, as a perpetrator of norms in society, needs to be accounted for as well. The “state legitimizes the activities of the corporate sector in the health arena” (Singer and Baer 1995:66). Health is something that can be bought at certain cost,
inaccessible to certain people and working for the benefit of others. The fact that medicine is a profit-making venture is often ignored. This however, illuminates just how much the institution is part of the larger cultural and social structures of capitalism in the United States.

Definition and Development of Biomedicine in the United States

Biomedicine, Western medicine, or “cosmopolitan medicine” is the type of medicine most often practiced in the United States and is culturally specific (McElroy and Townsend 1985:106). It stresses the value of technology, a sense of control over the environment, and places professional care givers in a hierarchical, specialized role (McElroy and Townsend 1985:106). This type of medicine took on the classification of “scientific medicine” and a position of authority over other methods (Singer and Baer 1995:187). Medicine must be seen as more than a thing and in fact, as a social relation (Navarro 1986:247). I would like to position biomedicine and its rise to the position of dominant medical system within the context of capitalism in the United States and its political and economic repercussions. “The emergence of the culture of capitalism has left little in our lives untouched—it has affected our material, spiritual and intellectual life; it has reshaped our values; and...it has largely dictated the direction that every institution in our society would take” (Robbins 2002:7).

The power of biomedicine accumulated because it worked to serve the interests of the corporate class institutions (Brown, R. 1980:1). Health, care, and medicine are rationalized under economic terms, so that services are available to those in need “at the least cost to society’s resources” (Brown, R. 1980:9). By promoting health in the very physical sense of the definition, medicine is able to support capitalism, by caring for those people that are needed as the producers. This action improves the health of society under the definition of the capitalists,
by having productive workers (Brown, R. 1980:10). Health becomes a unifying force and many refer to the institutional domain of medicine as the “industrial society’s counterpart to religion” (Brown, R. 1980:125). There is no self-analysis and the place of suffering is located in the disease and the individual, without looking into the possible social and cultural influences (Brown, R. 1980:129).

Care and services are reduced under the ideology of less government involvement. The market becomes “more efficient than the government in regulating the cost and distribution of health resources” in this environment (Navarro 1993:56). The 1980s and early 1990s in the United States were marked by an increase in funding for national security and the military (Navarro 1993:69). This plan cut money from social services and was in turn detrimental to the population’s health. There has been and continues to be the “attempt to replace services with commodities that can be bought and sold” (Navarro 1986:30).

Hegemony of Biomedicine – Health as a Commodity

Health is defined in the terms of those in power. In 1968, the World Health Organization defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (Dubos 1968:67). Yet, is this the definition every individual holds as the ideal? How can treatment or medicine purport to be the way to perfect health, when definitions of such may vary even within a culture?

Biomedicine asserts power, money, and authority over rival systems (Singer and Baer 1995: 187). The capitalist class can influence the way in which health care is funded, distributed, and delivered to recipients because of its control over services (Navarro 1993:12). Disease and illnesses in the United States are predominantly defined under the rubrics of
biomedicine and germ theory. According to Foucault, the fundamental act in medical knowledge, is the creation of a map, that positions, “a symptom in a disease, a disease in a specific ensemble and this ensemble in a plan of the pathological world” (1973:29). One does not consider the balance of the four humors of the body as is done in many eastern traditions, but instead attempts to see the physiological symptoms and the pathological entities causing them, emphasized in biomedicine.

The hegemonic role of medicine in society contributes to the influence that biomedical norms and beliefs have in the cultural models that mainstream members of the society hold about diseases and illnesses. Models of disease are grounded in looking at germs, bacteria, and foreign material entering the body. Our knowledge about health and illness is defined in these terms. Such definitions do not function within other domains or even other medical systems, alienating people who seek care that falls outside of mainstream cultural beliefs. Besides this dominating power of scientific medicine as the natural and logical definition of health and disease, what is also forgotten or silenced are the ways in which institutional norms and beliefs can influence disease and define one as being sick, further alienating people from the mainstream culture which upholds health as necessary for participation.

We are granted the limited “agency” to diagnose ourselves and purchase over the counter medicine. Yet this is just another piece of evidence that we live within a culture that supports the myth that “good health can be purchased” (Nichter 1991:1). In 1991, the cost of health care was equivalent to 11% of the US gross national product, but what has this spending achieved when there are cut-backs in services and increases in insurance payments? (Nichter 1991: 7). Discrepancies in access to the medical system can increase susceptibility in certain populations. Access to health follows the lines of the hierarchies permeating the capitalist system, so that
those with money and power have a greater chance of maintaining health as defined by mainstream culture and biomedicine.

**Capitalism, Ideology, and Medicine**

When examining an institution such as biomedicine, the interrelationships between the medical system and the political structures at work in society cannot be avoided. Even though biomedicine is often described as science, CMA posits it as a social construct. "All medical systems, including biomedicine, are cultural systems rooted in particular social traditions and socially constructed world views" (Singer and Baer 1995:12). Young was one of the first to challenge this view with his assertion that "science produces facts, it does not uncover them" (Singer and Baer 1995:12). Science is a type of production and what it details are then commodities.

There is a failure to acknowledge the impact of social relations, which legitimizes the existing social arrangements (Singer and Baer 1995:41). In order to develop a socially informed view of the phenomena with which one is faced, there needs to be a "recognition that science and its concepts are culturally created and as a result cannot help but incorporate tenets of the dominant ideology" (Singer and Baer 1995:50). Weber and Geertz emphasize how everything is suspended in webs of significance, "composed of things that stand for other things" (Singer and Baer 1995:82). "Meanings are developed and imposed by human beings" (Singer and Baer 1995:82).

"It is becoming increasingly evident that the capitalist system, is pursuing a direction which distances it from what people need most" (Lodziak 1995:ix). The system seeks to secure stability and alienates itself from the people that must live under its domain. There is a lack of
input and control from the ordinary citizens, yet the institutions manage to increasingly be the organizers of the citizen's actions and thoughts (Lodziak 1995:22). This may even extend into the cultural models that one holds about particular aspects of life. One may not be able to cognize the connection, but an outside observer looking at a pattern of beliefs, may see how the organization and structure of thoughts and models may link back to the economic and political ideologies in which one participates.

Social reality is infused with the dominant ideology of capitalism and in so far as the "social reality is lived, the dominant ideology is lived" (Lodziak 1995:30). Life becomes routine and something such as consumption or watching television is not analyzed, so that one might not see the alternate functions of the activities. We consume, and we produce, and we spend large amounts of time working for others and not ourselves (Lodziak 1995:57). "Our dependence on the capitalist system stems from the fact that it is the system that controls the resources we all need to survive" (Lodziak 1995:53).

The ideologies of the institutions of society are seen as influencing medicine in the same way. The capitalist ideology "reinforces and rationalizes the economy and social structure" so that people can make sense of the world according to the one dominant worldview (Brown 1997:124). It can also be described as "socially constituted knowledge" that is, a "product of evolving social forces" (Morsy 1996:29). Ideology sets the terms of discussion and discourse, thereby constructing a set of beliefs necessary for coherency (Singer and Baer 1995:62). The ideology of capitalism serves the goals of the system, by promoting particular actions and beliefs. The system is founded on the basis of furthering the abilities "of one class to control and expropriate the labor of the other class" (Singer and Baer 1995:61). CMA seeks to see the way
in which the ideologies of the dominant systems of a culture penetrate and influence the ways in
which people think of health and disease.

**Individualism**

Individualism promotes a view in which we are not interconnected, but single entities
responsible for ourselves. “We squander social capital in the name of economic growth”
(Robbins 2002:376). Across countries, as there is advancement economically toward capitalism
and the free market, there is a value shift toward individualization (Ester, Halman and de Morr
1994:1). The ideology of individualism emphasizes success as a result of one’s own efforts, but
in turn "promotes an anti-cooperative and anti-collective ethic" (Lodziak 1995:76). This moves
analysis away from institutions and the societal context in which problems exist. One is not to
identify with others or cooperate with one another. Blame placed on the ominous system, does
not solve the problem in this framework. People experience a feeling of a lack of autonomy and
power; they cannot find meaning or satisfaction (Lodziak 1995:78) They are cut off from the
people around them who are often experiencing the same feelings.

Following the shift to individualism, there is a similar movement toward the creation of
differentiated social structures. If differential structures are a part of the very nature and success
of capitalism, then the patterns of contact with something such as disease are subject to a
"hierarchical diffusion" (Robbins 2002: 241). The answer to the question of “what determines
the relationship that we have with the infectious pathogens whose world we share?” takes on a
whole new meaning within the hierarchy of capitalism (Robbins 2002:224). Segregation and
classification based on class, race, and gender take place throughout society. For example, the
treatment, or lack there of, of AIDS by the United States’ government when it was first
discovered was "largely based on the assumption that it was a homosexual disease" (Robbins 2002:244). Social norms create or reinforce stigmas, that when combined with physically dangerous conditions, can marginalize certain sectors of the population with the same illness, but not members of another particular social category.

Mind and Body in Biomedicine

One distinction made very clear in biomedicine is that of mind and body dualism. From this arises a "failure to conceptualize a 'mindful' causation of somatic states" (Lock and Scheper-Hughes 1996:47). The disconnect between mind and body contributes to the lack of a vocabulary to relate mind, body, and society (Lock and Scheper-Hughes 1996:48). Furthermore, the "precise analysis of the human body into its component parts is analogous to the industrial organization of production" and man as a machine (Brown, R. 1980:119). Dubos describes how medicine is taken over by scientific medicine and disease is the "derangement of the body machine" (1968:90). With a lack of conceptualization outside the individual and the physical body, the burden of disease is placed on the person and the societal and cultural contexts in which the disease and illness are experienced are erased.

Biomedicine's definition of disease as only a physical reality and therefore separate from human consciousness, places the responsibility for health on the individual (Singer and Baer 1995:79). The body is represented in ways separate from the social (Rhodes 1996:173). Therefore disease and sickness are associated with not acting responsibly, for each person is in control of their health. There is a contradiction between diseases as separate entities and disease as a result of particular behaviors. "Medical discourse narrows the scope of potential action to the individual level" (Singer and Baer 1995:27). This kind of non-critical perspective limits the
influences on health of which people are able to conceive. Lacking the discussion of other possibilities besides personal fault furthers their participation in a "social system that is often a major source of their personal problems" (Singer and Baer 1995:27).

"For us the human body defines, by natural right, the space of origin and of distribution of disease... There have been, and will be, other distributions of illness" (Foucault 1973: 3). The body becomes the sole receptacle for disease, missing the mental conceptions, beliefs, and the connect between not only the mind and the body, but also the mind, body, culture, and society. Medicine comes to define "the model man" and "embrace the knowledge of the healthy man" (Foucault 1973:34). The definitions based on the physiological categories for health in the medical system, immediately separate one from culture and society. Those who have a disease identified by biomedicine, are the sick and unhealthy. The hospitals and doctors do not produce wealth, rather they treat, health, "that which measures and produces wealth" (Foucault 1973:79).

"In the clinic, the patient is the case, the transitory object that it happens to have seized upon, the accident of his disease" (Foucault 1973:59). The person as a member of a culture and groups in society, becomes the patient, the subject of the clinical gaze.

CMA tackles the very nature of the way in which the sufferer's experience is constructed in biomedicine. Individuals are turned into "patients" who become "depersonalized sites of an isolatable, treatable disease" (Singer and Baer 1995:73). The human is removed from the situation and the disease is a pathological entity affecting a body constructed as functioning just like a machine. De Beer states that, "A sick individual is regarded as a set of physical symptoms, rather than as a person who belongs to a social class in a particular society" (Singer and Baer 1995:27). There is a complete denial of human relationships "embodied [in the] symptoms, signs and therapy" used in biomedicine (Singer and Baer 1995:76). This process of
reification clouds the reality of the properties of social relations as only correlated to the physical
correlation to the body and the disease, germ, virus, or bacteria.

Power Relations

The authority of biomedicine to diagnosis and treat what biomedicine itself defines as
disease, gives the institution an enormous amount of power over individuals seeking care. For
instance, someone who does not want to have a typical procedure is often portrayed as resistant
to authority and is characterized as having an individual pathology (Singer and Baer 1995:76).
Biomedicine functions in treating these kinds of pathologies. Illness is potentially dangerous, for
in many life threatening or life changing situations, people will examine everything around them
a bit closer (Singer and Baer 1995:83). There may be an awakening of new perspectives,
perhaps in contradiction to mainstream norms and beliefs. Medicine serves the critical function
of treating this “dis-ease,” reinforcing acquiescence and maintenance of existing systems (Singer
and Baer 1995:83). Medicalization serves the latent function of the resolution of social conflict
for the advantage of the dominant classes, both politically and economically (Singer and Baer
1995:33)

Even the doctor patient relationship is one laden with power and control. There is a great
dependence on medical professionals by individuals in society. The doctor is “endowed with the
power of decision and intervention” (Foucault 1973:89). This asymmetry is a “microcosm for
the reinforcement of subordination” (Singer and Baer 1995:85). As with capitalism, there is a
line drawn between those with power and those without. The physician can be characterized as a
Gramscian intellectual of the urban type, for the physician serves as the intermediary between
the capitalist class and the working class (Singer and Baer 1995:35). Although all doctors are
not seeking to dominate their patients, the status of medicine in society still dictates a relationship of inequality. The institutionalization of medicine embodies many of the ideals and norms of the economic and political structures of the United States.

**Public Interest Anthropology**

People are socialized and enculturated into mainstream culture full of norms, beliefs, and expectations. Actions and opportunities within this context are stratified based on opportunity and power. “Social performance is defined in terms of those actions admitting an individual into the opportunity structure of the U.S. public domain, enabling individuals or groups to function effectively within the mainstream social system” (Sanday, xxi). Public interest anthropology addresses the way in which the hierarchies of power should be conceived of in all contexts to capture the entire situation. Anthropologists working with the ideals of public interest anthropology strive toward “understanding the reasons for the disequilibrium in the distribution of power, resources, and rights in the United States” (Sanday, xxiii).

Recognizing the “growing ascendancy of multiple voices” is essential for public interest anthropology (Sanday 1997, 1). Without such a realization, the interests of “traditionally disenfranchised groups in U.S. society” will remain silenced and ignored (Sanday 1997: 1). There is now more attention being paid to expanding access to a wealth of services, giving groups and individuals a greater chance to speak for themselves and define what is of interest to them. In this vein, health is one the issues that has moved to the forefront of the public discourse.
Public, the Public Sphere, and Interest

It is important to define the notions of public and public sphere so that the specifics for the Philadelphia hepatitis C case can be seen within this framework. Power is present in the arenas that encompass the public. In simple terms, the public “refers to the plurality of individuals residing in a country and regulated by a body of laws defining rights and duties” (Sanday 1997:2). “The opinion of mankind spreads through myriad unlinked acts of transmission, as I said, while public opinion is formed by the participants together” (Taylor 1995:261). There is the acknowledgement of everything coming together to come to a “common resolution” (Taylor 1995:262). In this sense, all of the people living in the United States can be defined as a public. “The public sphere is, then, a locus in which rational views are elaborated which should guide government” (Taylor 1995:264). It is an “extrapolitical, secular, metatopical space...” (Taylor 1995:271). A public sphere is essential in a democracy and if one wants to foster freedom and equality, then the processes that enable such an entity to exist must be elucidated. Habermas describes this as “a theater in modern societies in which political participation is enacted through the medium of talk” (Fraser 1996: 110).

However, within this general sense of public, there arise specific groups and circles with particular interests and actions, living under more specific rights and duties, particular to certain sectors. Therefore, within a larger public, there may exist many other smaller publics. In fact, the construction of the public sphere as described by Habermas, was indeed constructed on the basis of exclusions (Fraser 1996:113). It is often overlooked that such a formulation was highly dependent on the institutional bases already in place (Dawson 1994: 210).

There was and is a construction of an “acceptable, patriotic American discourse” as part of the public sphere. Countercultures voicing divergent opinions are portrayed as anti-American
when in fact they may be working to realize the ideals of democracy and equality. It is argued that “a prerequisite for democratic debate is the recognition of the humanity and dignity of all individuals within a community” (Dawson 1994:220). Recognition of competing public spheres is necessary to account for the social processes observable today and in the past. A definition of public can also include the “social arena where macro-social questions concerning basic rights and the common good are negotiated, decided, and acted upon” (Sanday 1997:2). It is important to see the way in which multiple publics are organized not only in relation to each other, but also within the hierarchy of social institutions.

Within the very name of public interest anthropology, lies another term, which requires defining. Interest can be seen as “goals developed by or for a particular social collectivity to enhance or preserve its common good” (Sanday 1997:3). Working for the ideals of democracy and human rights, public interest anthropology defines itself as never being relativistic. However, it is important to define the interests in terms of the specific groups to which they are important. As anthropologists, one can define the interests in relation to one group, but it is likewise important to identify other publics and interests, which might be affected by the interests of the groups they are investigating.

Civil Society and Power

The place in which publics form is commonly referred to as civil society. This can be defined as “the social loci falling between the state and the private sphere but overlapping with both” (Sanday 1998:1). Civil society is the “zone between the individual and the state” and the networks of associations act as “social glue that bind together society” (Kawachi 2000:58). Within the United States, civil society is grounded in the macro-social guarantees established by
democracy. Taylor addresses the way in which there have been “a set of changes in the way we have come to imagine society” (1995:x). There is a perception of participation in public spheres and the exchanging information and ideas. “We think there is something called ‘society’ distinct from and sometimes in opposition to the state” (Taylor 1995:x). This arena has been the place in which groups define interests and often contest what it thought of as the state. Taylor defines civil society as “a web of autonomous associations, independent of the state, which bound citizens together in matters of common concern, and by there mere existence or action could have an effect on public policy” (1995:204). This is where the public has power and the people’s voice can be expressed. Civil society as defined above, distributes power among independent agencies.

The ways in which power is in fact possessed and expressed, is where the role of the anthropologist becomes important. It is in this domain, that a clear perception of social interaction and cultural norms illustrate to what degree a civil society can and does exist within the United States. With the notion of civil society, comes the sense that society does not have to be defined in terms of its political organization (Taylor 1995:210). However, this depends upon the way in which political is defined. Conflating political and the state, one dismisses political in the sense of power and action which groups outside of the typical state institutions can possess and articulate. Behind the organizations of citizens, lies the notion of subjective rights. “The superior had obligations as well as the inferior” (Taylor 1995: 211). This allowed for the questioning of policy and the checking of power and domination by groups seen as outside the state. It was important for the development of the public sphere that the opinions connected with society were “elaborated through no official, established, hierarchical organs of definition” (Taylor 995:211).
RESEARCH DESIGN AND METHODOLOGY

Background for Development of Liver Disease Questionnaires

Recent developments combining the methodologies of biomedicine and the social sciences have evolved into many new approaches for looking at illness and disease. This combination of models can better address a holistic approach to the health related quality of life of people, by using the broad foundation of the basic sciences and a more specific approach incorporating a psychosocial and economic foundation (Younossi et al. 1999:295). This relates to the way in which people perceive their specific disease and the manifestations it has in their lives. Essentially, it is more of an attempt to elicit the models that individuals have helping them to make sense of and attribute meaning to a disease in relation to their lives. Looking at quality of life, aims to address interventions with patients so that they can feel better. This involves treating not just the biological and physiological processes, but taking a holistic approach to treatment by addressing the psychological, emotional, and mental spheres of the person.

Research has indicated that HCV has effects on quality of life, but these are still not very well understood. Including the other studies already mentioned, it has been shown that patients with HCV and end-stage liver disease have higher levels of psychological distress and depression than people with end stage liver disease from other causes (Singh et al. 1997:407). Living with hepatitis C, there is the constant and long-term question of if or when the person will experience life-threatening symptoms. Some people live with HCV without ever having complications and others can develop very serious complications shortly after contracting the disease. Therefore, most often there is the element of uncertainty associated with this condition.
To analyze quality of life as it relates to hepatitis C specifically, an instrument specific to the disease was developed by Younossi et al., so that small variations particular to the disease can be taken into account. This quality of life questionnaire was developed to address emotional and physical health using 29 questions in 6 domains: fatigue, activity, emotional function, abdominal symptoms, systemic symptoms, and worry (Younossi et al. 1999:296). All questions were closed ended and responses were based on a seven point scale. This questionnaire was found to be easy to administer and results correlated with the severity of the liver disease (Younossi et al. 1999:297).

Questionnaire Development

Part of the questionnaire I developed and gave to the fire fighters was based on Younossi et al.'s chronic liver disease questionnaire, for its disease specificity (Appendix). The seven point scale was used for these questions, so that results could be compared. These questions dealt with feelings of anxiety, concentration, unhappiness, worsening of condition, and worry. These were used to elucidate the ways in which hepatitis C might influence one's overall mental health and the model that one held of the disease in relation to being able to cope with the symptoms and conditions. Self-described measures of health can help to determine the way in which diagnostic medical information affects an individual and if indications of well-being from biomedical discourse influence one's own conceptualization of health.

The first twelve questions were for all firefighters and the remainder of the questionnaire was for only those people with hepatitis C. The first twelve questions gathered background history related to being a firefighter and living in Philadelphia. The questions also focused on how the individual learned about hepatitis C, the disease's relation to the occupation of being
firefighter, education about the disease, and the role the city has taken on this issue. The questions developed for people with hepatitis C focused on mental, physical, and emotional health. Also addressed were social relationships and the impact of the disease in certain settings. Questions regarding support networks were also asked along with the number of people that were aware of the person’s condition. Several of these questions were based on a patient interview form used by the NHCLS in their surveillance study for CLD. These questions were framed to describe one’s health and well-being over a given time period and in relation to other times. Specific to the firefighters, questions addressing the role of their training and job experience were also included. Finally, questions about treatment were raised to elucidate one’s relationship to the medical community or other forms of health support.

Because of the sensitive nature of such material and its relation to medical health, I applied to the Institutional Review Board (IRB) for exemption from review. Exempt status approval for this study was granted by the University of Pennsylvania’s IRB on January 18, 2002. All material was gathered anonymously and I was not present at union meetings due to the regulations of the fire fighters’ union. Questionnaires were mailed back to me in prepared return envelopes. This questionnaire qualified for exempt status because it did not involve invasive techniques and participation was completely voluntary.

(http://www.upenn.edu/regulatoryaffairs/index.html : Jan 2002)

**Questionnaire Limitations**

The semi-structured questionnaire developed for this study involved mostly open-ended questions to enable the firefighters to express their own ideas and points of view. I did not wish to include closed ended questions for the bulk of this study. This would have been imposing
categories on the participants that may not have correlated to their own personal conception of the disease. This might have increased the response rate, but would have resulted in presenting more of my own views rather than the participants'. Even the issues addressed in my questionnaire were selectively chosen because of the limited space and time for such a study.

The length of the questionnaire was significant and may have been a deterrent for some people. Additionally, the fact that the questionnaire was asking about hepatitis C and its impact may have influenced the response rate. This population in particular, has been bombarded with information on this topic and involvement in another study may not have been seen as important. The sensitive nature of the disease may also have led some people who are hepatitis C positive to not respond. Hepatitis C may also be something that is not talked about and moved aside. For certain individuals, it may also be conceptualized as something that it not really affecting their lives and therefore they did not even give time to answer a questionnaire about it. Denial of the disease and its impact may also have played a role in some people not responding.

Study Limitations and Alternate Research Methods

Direct participant observation would have been much more ideal for illuminating the everyday lived experiences and cultural models of this disease. However, there were certain limitations, which made this option not viable. First, there were the regulations of the union, so that I was not even able to present my study to the firefighters. It was impossible to attend the union meetings. Second, the confidentiality issues surrounding hepatitis C meant that not even the union was aware of everyone that had hepatitis C. To observe interactions would not have been fruitful, for the number of people with HCV involved in specific situations would have been unknown. Finally, there was also the fact that the issue of hepatitis C compensation under
work benefits was being heard before the legislature during the time at which my research began. Although not explicitly stated to me, there may have been union recommendations or restrictions concerning talking to outside groups about this issue.

In combination with the questionnaires, I researched and analyzed websites, literature, and newspapers, to illustrate more fully the situation of the Philadelphia fire fighters and hepatitis C. This study can be seen as a guide for future projects looking at disease in highly specialized groups, as the amount of newly collected empirical data is not as large as necessary to provide sound findings for this cohort. A study of this nature would have taken a much longer time and the very nature of the organization chosen was somewhat limiting. However, the limited access is telling on its own and contributes to the specific situations that this group is dealing with now and will continue to face in the future.

RESULTS

Construction of Hepatitis C in the Public Sphere

It now becomes important to trace the emergence of Hepatitis C in the public sphere as framed by the Philadelphia fire fighters and the union. This information was obtained from news sources and internet material pertaining to the course of events as presented by the media, the local fire union, and the international unions. Because of the very sensitive and political nature of the situation, the amount of information I was able to obtain was limited.
Media Coverage

Union descriptions in October of 1999, called hepatitis C a “deadly virus” and “an epidemic” (AP 1999). Reports of 25 fire fighters contracting the disease from on the job exposure emerged. Contraction was attributed to exposure to contaminated blood while responding to accidents and emergencies prior to the mid-1980s, when masks and gloves, now a standard part of universal precautions, were not required equipment. The level of infection control in Philadelphia was less stringent than in some suburban squads because in many states, the Occupational Health and Safety Association has not had authority over sectors of the municipal government (Lin 2001:A01). Fire fighters cited the city’s bankruptcy as a reason for the lack of basic equipment and cutbacks in safety measures in the late 1980s.

There was somewhat of a divide on where to place the blame as others were self-critical and saw both fire department administration and the “firehouse culture” at fault (Lin 2001:A01). Blood was something that fire fighters wore proudly. It was not to be feared, but rather a sign of doing one’s job. Some union members described how the ignorance about the ramifications of such a value contributed to the situation with which they were now faced. They even noted that the “mind-set of the rescue worker -- the bravado of invincibility -- may have encouraged laxity” (Lin 2001:A01).

With the report of the 25 fire fighters with hepatitis C, the union requested a voluntary testing program to ascertain the true prevalence among the city’s 2,400 active fire fighters (AP, 1999). The larger request that the union had, was for hepatitis C to be “classified as a job-related illness and the city to help pay for the cost of medication to treat the disease” (AP, 1999). In December of 1999, the Philadelphia Daily News reported that 125 fire fighters or 6% of those tested were HCV positive (Brown, J 1999:8). The union described these results as “devastating”
and saw the city as not responding to the claims of the fire fighters. Dr. Kenneth Rothstein of the Albert Einstein Medical Center, who is treating many of the fire fighters, was quoted as saying, “It’s most likely this is due to occupational exposure” (Brown, J 1999:8).

A year later, the issue in Philadelphia came to light in other counties of Pennsylvania. Additionally, other major cities reported having higher rates of hepatitis C than the national average of hepatitis C. It was said, “fire fighters respond to accidents more often than they do fires” (Espenshade 2000, A-12). Again the issue of a lack of universal precautions was blamed for increased risk of contraction of the disease. Outside of cities, the concern was not as large. Philadelphia was painted as an inner city with the problems of drug users, concentrations of the poor, and populations with higher rates of other behaviors such as drinking and sexual promiscuity (Espenshade 2000, A-12).

The illumination of the hepatitis C problem finally resulted in proposed legislation at the state level. However, even in October of 2000, a year after the problem was brought into the public arena, the measures had not been passed. The state had allocated $2 million to pay for testing, but no other measures had been proposed, nor had the previously proposed bills been passed (Espenshade 2000, A-12). Philadelphia fire fighters were backed at this point in time by the International Association of Fire Fighters, in addition to their local union. The unions asserted that “fire fighters who do rescue work and medical runs, as well as EMTs and paramedics, are at greater risk of contracting hepatitis C on the job” (Espenshade 2000, A-12).

Centers for Disease Control and Prevention Report

The assertion by the unions and the fire fighters of contraction from on the job exposure was met with opposition with the release of the Centers for Disease Control and Prevention
(CDC) report looking at occupational exposure to blood borne pathogens by first responders. In July 2000, the CDC said that fire fighters, EMTs and paramedics, “are not at a greater risk than the general population for hepatitis C infection” (Centers for Disease Control and Prevention 2000:660). This meant that the CDC did support HCV testing for all first responders.

In February of 2000, a private testing firm offered testing to the 4,400 active and retired Philadelphia fire fighter union members. Of 2,146 participants, 97 (4.5%) tested positive. This placed prevalence at 2.5 times the national average of 1.8% (Figure 7). The report demonstrated that this information, describing the prevalence of HCV in Philadelphia’s fire fighters, was inaccurate due to inadequate amounts of blood for supplemental testing to verify positive results when the CDC conducted a similar testing procedure in June of 2000, of the 2,136 participants, 64 (3.0%) tested positive. A questionnaire distributed by the CDC also determined history of a blood transfusion and illicit drug use as risk factors associated with HCV infection.

The CDC report also highlighted the fact that within the general population higher rates of hepatitis C existed among men aged 30-49 in 1994. This section of the population was now 40-59 and made up a large part of the population of the fire fighters being tested. Therefore, high rates had to be considered against the general population by taking into account the composition of the sample. (Centers for Disease Control and Prevention 2000:660-665)

Emotional Outcries and Public Support

Public support to counter the report by the CDC was evident in the local media at this time. The union was able to frame their concern in a manner it and the general public considered logical. Fire fighters had greater exposure based on the fact that they dealt with blood on the job, and a reporter, a teacher, or a cashier did not. In the public arena, the plight of the fire fighters
emerged connected to individuals, giving others the ability to see the impact on everyday life for people just like them. There could be a personal identification with the afflicted. The union was working to counter the alienation associated with disease constructed by other discourses.

One of the most public and emotion evoking events of the struggle between the Philadelphia fire fighters and the city took place on December 6, 2000. This was a sit-in at City Hall by one of the paramedics who had hepatitis C. Lt. Mary Kohler began the sit-in saying that she would not leave until Mayor John Street recognized hepatitis C as a work-related injury and increased the health insurance for first responders (Loviglio 2000). Kohler was about to run out of sick time and suffered from “agonizing joint pain, chronic fatigue, and tremors” (Loviglio 2000). Street said he had great respect for these men and women, but could not “be dragged into individual cases, because, I’ll tell you, I don’t know how I would draw the line” (Loviglio 2000).

Mayor Street and the city council refused to acknowledge the ruling of an arbitrator that gave the fire and rescue workers the victory in this battle. The ruling called for $4.8 million over two years to go to health and welfare plans, a 7% pay increase over two years, and to reinstate or reimburse sick leave used in connection with hepatitis C (Loviglio 2000). The city had not followed these guidelines, citing a 1991 state law that “allows Philadelphia to appeal police and fire arbitration awards” (Loviglio 2000).

State Legislation

In contrast to the opposition from Mayor Street and the city of Philadelphia, the fire fighters found support in the state Legislature. In January 2001, news reports indicated that 225 fire fighters and paramedics had tested positive for HCV (Rubinkam 2001). W. Curtis Thomas Philadelphia’s Democratic representative in the state Legislature introduced legislation to make
hepatitis C a “presumed ‘occupational disease’ for professional and volunteer fire fighters, paramedics, and other rescue workers across the state” (Rubinkam 2001). Citing the precedent that state law covers hepatitis as a work related illness for nurses, blood processors, and auxiliary services, the proposal was met with great support. Rep. Michael McGeehan also from Philadelphia said, “It doesn’t take a rocket scientist to find out...that these men and women contract the disease on the job” (Rubinkam 2001). The state officials framed this fight in ethical and moral discourse and felt they were “morally obligated to protect public safety workers” (Wiggins 2001:B01).

The union was also able to frame the need for this coverage in light of the fact that Philadelphia “lags behind federal regulations and the efforts of other cities to protect its emergency workers from hepatitis C” (AP 2001). Philadelphia was found to be the only city out of seven other large urban areas to not conduct mandatory and annual training for infection control (AP 2001). However, Street opposed the measures, under the claim that such coverage would cost taxpayers $10 million over five years (Lin 2001:A01). The union at this point in time stated, they should not even have to be fighting for this issue. They were relying on the fact that other cities take care of their workers and Philadelphia should do this without a fight from the fire fighters themselves. The City Controller, Jonathan Saidel publicly stated his support for the fire fighters, “…we have to put safety first and cost-consciousness second” (Lin 2001:A01).

One year after the 15-day sit-in at City Hall, a bill was passed by the state Legislature. In reports leading up to the passage, the number of fire fighters the union reported to have hepatitis C increased to 250 (Caruso 2001). After debate over versions of the bill in the House and the Senate, Governor Mark Schweiker signed the bill into law on December 20, 2001. Kohler expressed the sentiments of the fire fighters when she proclaimed, “We beat City Hall” (Marshall
2001). When signing the bill, Governor Schweiker noted that fire fighters are around when blood begins to fly and the death of two people from HCV must be seen as an extremely important issue. He in fact praised the fire fighters for drawing attention to the issue (Marshall 2001). The legislation required that the burden of proof be on the municipality to show that disease was acquired when the person was not working. Another amendment to the measure was pre-employment screening for HCV (May 2001). The costs for hepatitis C shifted from the union health insurance plan to the city.

Fire fighters, paramedics, and police officers can now apply for workers compensation benefits in Pennsylvania (Marshall 2001). In February 2001, Pennsylvania joined eight other states in offering benefits to fire fighters for hepatitis C and four other states in covering emergency workers, and law enforcement officers (Wiggins 2001:B01). In September of 2001, it was reported that 15 states have passed laws to allow public service workers, including volunteers, to collect compensation for contracting hepatitis C on the job (Lewis 2001:MD01).

**Questionnaire Results**

Questionnaires were distributed at two Local 22 union meetings by my contact person, the union's recording secretary. The union restricted my access to the meetings, so I was unable to be present at the monthly meetings, which typically have an attendance of 100-120 members. At the February union meeting, 120 questionnaires were distributed and at the March meeting, another set of 60 questionnaires was distributed. My union contact announced at the meetings that the questionnaires were present. I had made signs, so that people could pick them up from
the designated locations. Five questionnaires were returned to me via mail before the March meeting and an additional three have been returned since the March union meeting.

Questionnaire Responses – All Respondents

Five of the respondents report that they are hepatitis C negative and three report that they are hepatitis C positive. I therefore have eight sets of answers to the first twelve questions and three sets of responses pertaining specifically to the questions on living with hepatitis C. I would like to first address the ways in which the first set of questions was answered by the firefighters with and without hepatitis C. All respondents have lived only in Philadelphia and when working as a fire fighter, have been employed solely with the Philadelphia Fire Department. All of the participants have been union members for the same amount of time as being fire fighters. Employment time ranges from 5 years to 29 years. Reasons across the two groups for becoming a firefighter include, to “protect and serve,” “to serve my own community,” wanting to be a “member of the civil service,” and the “excitement and challenge” associated with the job.

Most of the respondents state they had not known very much about hepatitis C until it surfaced in connection to their occupation. The ways in which they describe the disease before they were made aware of what it is, are probably comparable to what the general population of the United States knows about hepatitis C. In fact, the fire fighters also indicate they feel as though the general public does not know enough about hepatitis C. Descriptions include it being a “liver disease” and being “blood related.” However, most said they did not know about it at all. One fire fighter with only 5 years of work experience received training in fire school, but this is in contrast to the fire fighters that had been working for many more years.
Those people without hepatitis C report their gaining knowledge because "union members came forward," or a person in the firehouse contracted the disease. One of the fire fighters with hepatitis C learned about the condition from a doctor and the other from fellow union members. One of the respondents acknowledges the power of the union in Philadelphia and how people in Philadelphia may be slightly more aware of the disease, citing the "public relations efforts" of the union. The union's efforts are also reflected in the responses to what can be done to prevent the spread of this disease. The suggestions are very similar to those touted by the union, such as practicing universal precautions and implementing education programs.

All of the respondents without hepatitis C, worry about getting hepatitis C on the job. One respondent with hepatitis C says, "I love my job" and it is the "only thing that keeps me going" and has a great fear that work may not be an option soon. Writing about what they think it is like to have hepatitis C, the descriptions include "weak and in pain," "sick," terrible with "weakness and fatigue," and "agon, tiresome, painful, frightening." When asked it they thought it is the same for everyone, the responses of fire fighters without hepatitis C indicate there is a perceived subjective aspect to the disease. There is no conception of the disease as a single, known entity with specific symptoms. It is a personal experience, for the respondents describe seeing fellow fire fighters with very different cases, some "becoming suicidal" and others being "fine after medication."

Answers to a question regarding the city's involvement in this issue echo the sentiments expressed in the media, which covered the union's position on the situation. The word "nothing" is common in this response. One person says that in addition to having hepatitis C "they have to fight the city all the way." There is also the feeling that the city officials are only doing a lot of talking and there is the need to "stop debating." There is a division established between the city
and the fire fighters and one person describes this as the city officials “distancing themselves” from the situation and the fact that they “battled every member [of city council] with hepatitis C.”

Respondents with Hepatitis C

In addition to the questions detailed above, those respondents with hepatitis C also answered questions on the ways in which they perceive and conceptualize hepatitis C; illuminating it as an illness rather than just a biomedically defined disease. Because I did not ask about the severity of the person’s disease according to the biomedical standards other than a positive or negative diagnosis, the impact of the disease in terms of health both physically and mentally is all self described.

The impact of hepatitis C on daily activities of the three respondents ranges from no impact, to only being able to work and not being able to take care of other tasks because of being “weak and in pain.” The same range is present for status of physical health and mental health over the past 30 days. Likewise, when asked about health in general as compared to a year ago, one person reports being somewhat better, another reports somewhat worse, and another about the same. With just these three people, it is clear that there is not a set of prescribed outcomes for this disease. It is very individualized and the implications can range from mild to severe.

Responses to the questions that were based on Younossi et al.'s chronic liver disease questionnaire, vary. All three individuals report feeling anxious some of the time during the last two weeks. Two report having problems concentrating some of the time and one a good bit of the time during the last two weeks. Two were unhappy some of the time and one hardly any of the time. When asked about worry over their condition getting worse, the answers ranged from
all of the time to a good bit of the time. Two report worry about never feeling better, one some of the time and one most of the time.

Social Support Networks

I also developed questions to understand the impact hepatitis C has had on personal relationships. All three report that everyone knows about their conditions, listing family, friends, and co-workers. In their relationships with spouses, they report that is a bit “stressed” at times and the other person being “little scared.” All respondents also have children. The reactions among the children to the disease, may be more severe because the children may not understand all the implications. One respondent said the children are scared and “don’t want me to die.” Another reports being extremely cautious with the kids when there is any blood saying “I try to clean it up and cover it up quickly.” When asked how much of the time during the past two weeks they have worried about the impact hepatitis C has had on their families, all three reported intense worry. One says he worries “all the time, feel[s] guilty or scared” and another reports that he thinks about it “every waking hour.” Another says “[I have] come to accept it now,” but “thinks about it everyday.”

Relationships with friends and coworkers range from supportive, to some people being scared. The respondents noted that these people are now “more educated about hepatitis C” indicating that they were able to communicate to others and share their knowledge. They are taking on the disease and fighting against it by learning and educating the people around them.
Fire Fighters and the Medical Community

The questionnaire responses also brought out some of the unique relationship that fire fighters have to the medical community. They are intimately linked because they are the first responders to accidents and then bring people to hospitals, where they are cared for by people in the medical community. All three express their positive feelings about the medical community saying, that the “doctor is great, nurses are the best,” they have been “supportive and educational” and that there is a “special bond between health care workers and fire fighters.”

Unions

The fire fighter’s union was not able to gain support in the city, but through other means and by approaching higher societal levels, succeed in having legislation passed for the protection of first-responders against the costs incurred from hepatitis C contracted while on the job. The local union is part of two larger national and international level labor unions, with full support coming from both groups. One of these being the International Association of Fire Fighters (IAFF) which is a member of the American Federation of Labor and Congress of Industrial Organizations (AFL-CIO).

International Association of Fire Fighters

The IAFF represents 240,000 professional fire fighters and emergency medical personnel in both the United States and Canada (http://www.iaff.org/: Feb 2002). They represent state employees, federal workers, and certain workers at industrial facilities. Their website reports
that "members protect more than 85% of the lives and property and are the largest providers of pre-hospital emergency medical care in the U.S." (http://www.iaff.org/: Feb 2002). Describing its mission, "the union fights for the rights, health and safety of the vast majority of full-time, paid firefighters" (http://www.iaff.org/: Feb 2002). In existence since 1918, this union has helped to define the goals and interests of fire fighters and worked to enact certain objectives. The IAFF encourages the formation of local unions and the implementation of schools to widen the knowledge available concerning fire fighting, safety, and prevention (http://www.iaff.org/: Feb 2002). They seek also "to secure just compensation for their services and equitable settlement of their grievances" and "to promote harmonious relations between fire fighters and their employers" (http://www.iaff.org/: Feb 2002).

Because of the dangerous nature of the occupation, a large part of the IAFF’s energy is put toward voicing the health and safety issues faced by fire fighters. It is under this guise that hepatitis C is a concern to the IAFF. Being "fully committed to the political process" the union works with elected officials and makes them aware of and accountable for the policies they create (http://www.iaff.org/: Feb 2002). The union’s website has a comprehensive section dealing with hepatitis C and the disease’s relation to the fire fighters it represents. In a letter from IAFF’s General President, the union states its commitment to awareness programs, education, protecting the first responders, and acknowledging real-life stories and experiences with hepatitis C (http://www.iaff.org/hepc/frames/HCV.html: Feb 2002).

In August of 2000, the IAFF made an official statement on its policy toward hepatitis C. Among the declarations is that "members diagnosed with hepatitis C would be considered as exposed in the line of duty" (http://www.iaff.org/hepc/frames/HCV.html: Feb 2002.) This statement meant that the Philadelphia firefighters had not only local support, but also the
international support of the much larger union that was working to protect everyone in these occupational positions. With this assertion, the IAFF also stated its commitment to working for legislation at every level to provide benefits for workers with HCV because of the “presumption that infectious disease exposure occurred in the line of duty” (http://www.iaff.org/hepc/frames/HCV.html: Feb 2002).

American Federation of Labor and Congress of Industrial Organizations

The IAFF is a member of the AFL-CIO, which is composed of 66 national and international labor unions. It was founded in 1955, from a merger between the American Federation of Labor and the Congress of Industrial Organizations. According to the AFL-CIO main website, the union represents more than “13 million working men and women of every race and ethnicity and from every walk of life” (http://www.aflcio.org/front/about.htm : Feb 2002). The diverse nature of this organization has made it a foundation working toward the goals of equality for all human beings. The unions see themselves as working to “improve the lives of America’s working families, bring fairness and dignity to the workplace, and secure social and economic equity in our nation” (http://www.aflcio.org/front/about.htm : Feb 2002). To achieve these goals, the AFL-CIO works to strengthen the ability of people to join unions. The power of such a collectivity is realized, for the AFL-CIO sees itself as gaining stronger political voices through certain efforts. It likewise, works to promote a new voice of the workers of the global economy. In addition, it hopes to create a voice for working families in the communities they inhabit.

It is the self-proclaimed “single most effective force in America for enabling working people to build better lives and futures” (http://www.aflcio.org/front/about.htm : Feb 2002).
They specifically seek “livable wages, decent health and retirement benefits“ and have “led effort to promote democracy and democratic trade unionism across the globe” (http://www.aflcio.org/front/about.htm : Feb 2002). The union also works to “create opportunities for working people to make our voices heard in the halls of government” (http://www.aflcio.org/front/about.htm : Feb 2002). There is an effort to advance the ideals inherent in the political system of democracy. It seeks to “build a broad movement” of workers through unions, the powerful structure of a collective with self-defined interests.

**Philadelphia Local 22 Fire Fighter’s Union**

At the most local level is Local 22 of the IAFF, the Philadelphia Fire Fighters Union. This group identifies itself in much the same manner as its parent groups, clearly listing these affiliations. The union’s website is a rich source of information regarding hepatitis C (http://www.local22iaff.org/html/Homelist.htm : Feb 2002). The union’s website is interesting as well, because it is used as a place of contact for all members of the union. They can use this site to find out about, among other things, their work shifts, their union meetings, and information about hepatitis C. Therefore, this is a site of knowledge in the eyes of the members and gains a certain amount of power from this kind of usage.

The site traces the events leading up to and including the passage of the legislation for hepatitis C to be covered by workers’ compensation. It is touted as a “victory for all” and thanks those who worked for “our Brothers and Sisters” (http://www.local22iaff.org/html/Homelist.htm :Feb 2002). There are links to the popular media sources as well as internal links, to articles written for the Union’s own newsletter, *Under Control*. Featured are those stories, which show how Philadelphia does not have the same standards as other cities for its firefighters.
Updates about other states passing the legislation that the union worked for are also included. The material covers not only the political issues, surrounding the situation, but also the personal stories, as one article is written by Lt. Mary Kohler describing the impact hepatitis C has had on her life. The union president, at the time of the initial confrontation with the city, also clearly states the position of the union and criticizes the position that the city took, beginning with former Mayor Ed Rendell and continuing with current Mayor John Street. There is the clear distinction between the aims of the city and the human concerns of the fire fighters.

Being a resource for the fire fighters, there is also a section of hepatitis C related links to many organizations and groups that disseminate material on this disease. The union is attempting to increase the awareness of its members about this condition. Because so little is known about the disease in the general public, the firefighters, were most likely unaware of what it was until they were faced with it on the job either in training or because of the recent events in their workplaces. The raising of awareness continues outside of the members, with the advertising for a campaign for hepatitis C ribbons. These ribbons are being sold to raise money for those members with HCV and to educate the public about the disease.

Additionally, the site is a place to go for human support, not just educational support. The site is for personal exchanges as there are updates about people with hepatitis C, specifically Mary Kohler, who sat in City Hall until Mayor Street would listen to her concerns. There are links to her “battle with the city” that paint the picture of one person having to fight the system. There is also information regarding the sick bank, where members could contribute hours to fellow fire fighters undergoing treatment, before the passage of the legislation. The fire fighters
have created a hepatitis support group. The group targets all members of the union and their families. It addresses people with the disease to help with conditions from direct experience, but it is also for those members who are not HCV positive, but are concerned about the dangers of their job or want to offer support to their fellow fire fighters. "This disease has truly affected our loved ones among the membership and we are concerned for their well-being" (http://www.local22iaff.org/html/NewsPage.htm : Feb 2002). To protect those people with HCV who may not want everyone to know about their condition, the group stresses that confidentiality will be observed.

DISCUSSION

My access to information was in a sense a political issue because of the work being done by the union. Therefore, I see this analysis as shaped knowledge, but would also like to carry this observation to the very knowledge that the fire fighters had. The majority of their information during this time period most likely was coming from the union. This central source had a certain degree of power over the availability to and framing of information.
The Cultural Model of Hepatitis C

I would like to suggest that the cultural model and conceptualization of hepatitis C is greatly framed and constructed by the fire fighter's union. The fire fighters did not allow themselves to be identified as only patients, but instead as people holding a cultural model of hepatitis C as an illness with meaning. Hepatitis C was something that encouraged them to fight for their health, as they defined it. Symptoms did not keep this group from fighting for their rights. Disease and in turn illness, became the empowering force that biomedicine can often be seen as suppressing. It was the motivation to work for change. The fact that the majority of my respondents did not know about hepatitis C before and listed the union or fellow firefights as how they heard about and then learned about hepatitis C, places the union in a very powerful and strategic position in terms of educating its members about hepatitis C.

Analysis of Questionnaire Responses

I would now like to examine the responses to the questionnaire I developed, drawing on the theoretical literature on medical anthropology, public interest anthropology, and biomedicine.

The responses concerning why these people became fire fighters demonstrate the desire to be a part of a societal institution that functions to protect others. Fire fighters are in many ways regarded and respected for the dangerous nature of the tasks they complete. The taxing nature of the job makes the fire fighters a very self-selecting group willing to take the risks associated with fighting fires and being the first responders to accidents. They are the ones who salvage aspects of communities and societies that might otherwise disappear. They try to rescue not only people, but also buildings, in the face of the possible loss of their own lives. However,
rather than speak of these dangerous aspects in a negative light, the challenge of the job is
described as "exciting." Also, the desire to "protect and serve" another group in which the fire
fighter also identifies himself, ties these people to larger societal and cultural circles.

The worry concerning exposure on the job can have a strong impact on one's
conceptualization of a disease. It can emerge as a much larger problem, if it is seen as a threat to
the way in which one makes a living. This fear may be especially prominent in advanced
industrialized countries where work is central; for income is often connected to life chances and
opportunities (Marmot et al. 1999:107). Occupation "defines an important criterion of social
stratification" and is one of the most important functions and goals of socialization in
industrialized countries (Marmot et al 1999:107). People have been socialized to see work as
extremely important and threats to one's ability to hold such a position can cause great worry and
distress. Occupation is often a defining characteristic of self.

The city is an example of the hierarchical power structures, which the union and the fire
fighters confronted. One needs to assign import to one's social context and look at social
stratification and legitimized behaviors and norms of institutions (Diderichsen in Amick and
Lavis 2000:180). Looking at health and social hierarchy one sees gradients and disparities
between the top and the bottom (Amick and Lavis 2000:179). The union and the fire fighters
saw the divide between themselves and the bureaucratic institutions unwilling to help their
employees. The union was able to contest the authority of the city because of its power as a
collective group with a focused and self-defined interest. The respondents describe a problem
with the bureaucracy of the city government.

Social support networks are often very important in helping a person to be able to cope
and deal with difficult situations. Kawachi (2000:58) defines social capital as the "networks of"
secondary associations, interpersonal trusts, norms of reciprocity” which serve to “facilitate collective action for mutual benefit.” If people feel as though those they care about have abandoned them, the physical and psychological effects can be far reaching. The quality and dependability of one’s social characteristics influence one’s everyday life (Tarlow and St. Peter 2000:xii). Social networks are a measure of social integration and link the needs of one person to the larger whole of a society or a culture (Stansfeld 1999:156). It has been shown that social support can help people who have to adjust to chronic illness (Stansfeld 1999:164). This measure of social integration and cohesion can be extended to higher levels and is applicable to the fire fighters union. Extrapolating to the societal level, the “existence of mutual trust and respect between different sections of society, contributed to the way in which people and their health are cherished” (Stansfeld 1999:169).

The ability the respondents had to share information with friends, families and coworkers has most likely impacted the model that the three respondents with hepatitis C hold. It is not something they had to keep secret from the people around them. Although it may have been very difficult to divulge the information, to be able to talk about such a disease, can give the person a great deal of power over it. It is not an entity keeping the person quiet and closed off from the world and people around them. The fire fighters can talk about their illness with others and get help. Such discussions can involve biomedical discourse, but also bring in personal experience and feelings in their personal interactions enabling for a conceptualization of the disease full of their own meaning, not a prescribed one.

I would suggest that the union helped in educating this group of people, who could in turn then share information with a larger group, increasing the level of knowledge of those around them. Not only did doctors and the medical community inform them, but also the fire
fighters had the union’s website, the support groups, and their fellow firefighters with hepatitis C.

Looking at the relationship to the medical community, the fire fighters stand in a similar professional position in that they are respected for the job that they do for people and communities. With this in mind, it is interesting that they are able to accept a partial biomedical definition of their disease, but are also able to expound upon it to give it personal meaning. The fire fighters stand within the community that divorces the person from the disease, yet in individual experiences, they are able to reject the narrow definition of disease and make it an illness, adhering to the union’s cultural model. It is clear that they still rely on the biomedical community for education and assistance in terms of the implications of the disease, methods of contraction, and treatment options. Their position as part of the medical community may have meant a closer connection between the patients, in this case the firefighters, and the doctors and nurses. As people in the same area of work, there may have been a more personal connection and so the care they received may have been slightly different than a person who is not in the health care and safety field.

**Threat to Identity**

When hepatitis C is a threat because of what one does and then is potentially something that could inhibit one from working, it poses an enormous perceived danger to one’s identity as a person, a citizen, a family member, or a worker. As mentioned before, the import placed on one’s profession in the United States shapes one’s image of themselves in relation to a job. Job defines a person’s status as well as establishing a social network and creating specific goals within capitalist culture (Breakwell 1986:53). The meaning of one’s actions and movements is
predetermined and fit into the dominant ideologies of prevailing mainstream culture. Not being able to work threatens the identifications that one can make to others and society in general. Especially when looking at identity in relation to one’s job, it is evident that identifications are structurally and hierarchically marked (Holland et al. 1998:7). Identities occur in the world of social practice and when one is no longer able to participate in the realm in which much of the image of themselves has been created, they are placed into a precarious position.

Identity is a dynamic social product and rests in many psychological processes, which can only be understood in their social and cultural context (Breakwell 1986:9). Hepatitis C is a threat to the fire fighters because it could take away their ability to function not only as fire fighters, but then also in their other roles as members of families or communities of friends and neighbors. In light of the events of September 11, the impact of this illness may have been magnified for the fire fighters. The status of this profession was increased in the public eye. Not being able to perform one’s job in the time that they were needed most, could have increased the stress associated with being diagnosed with hepatitis C. The invincibility culture of the fire fighter would most certainly be displaced, making one question what has most certainly been a major part of one’s description of one’s social identity. Because social identity builds on group membership and interpersonal relationships, social positions are often translated into one’s conception of self, the threat in a social setting would then manifest itself in one’s ability to handle a chronic illness at a personal level.
Analysis of Strategic Positioning

I would now like to address the role that each participant group had concerning the coverage of hepatitis C under worker's compensation. The position taken by each group involved in this situation can be seen within the context of societal and cultural standards and norms. I position the city and the state as participants in the mainstream capitalist culture and as embodying the ideologies of this system. However, the city and the state took different positions, which may be due in part to physical distance or a shift of values as to which fights were most important. I also see the work of the union and the fire fighters as very different from the city, constructing a model of hepatitis C that appealed to an identity as a human being with personal experiences, goals, and understandings.

City of Philadelphia

Let us first look at the city and Mayor Street. Citing potential financial hardship, the city was unwilling to pay for compensation. There was an appeal to the citizens of Philadelphia to try to save tax dollars. To cover the costs of treatment for hepatitis C, would also have meant that the city was taking on some responsibility. The city was unwilling to take this actions. Before the December law, the union was covering costs, keeping problems internal to the fire department, even though the fire fighters were performing a city service on which many people depended. I see this as a manifestation of the economic goals of the city conflicting with the needs of its citizens.

However, the city’s position was referenced in a way to appeal to those people without hepatitis C, in the hope that they would see this as the fire fighters incurring costs for others. By
placing the financial burden on taxpayers, the interests of the city were made to be as looking out for its citizens. While denying safety measures, they could easily subvert the most obvious level of analysis and appeal to the ethos of individuality, seeking profit, and protecting oneself. The city also had the support of the CDC, a national institution, when it declared that exposure was not considered to be greater for first responders. The city was using scientific "facts" and economic guidelines to fight the fire fighters' appeals.

Being an institution within the capitalist system, the city was working within the mainstream ideologies of the free market and was unwilling to turn responsibility over to the larger collective. The fire fighters and the union were alienated by the institution of the city of which they were a part. Taking this position, the city reproduced the hierarchical structure of the government in relation to its citizens and even its employees. It sent the message that the fire fighters did not deserve treatment for this disease. They were portrayed as a collective with an unwanted condition and not as human beings suffering from a threat to their well-being incurred while protecting others.

The difficulty in proving the exact transmission route was also a point for contention between the city and the fire fighters. By not believing that the fire fighters had been exposed to hepatitis C on the job, distrust may have been detrimental to the well-being of those people who truly did contract the disease in this manner. Underlying the denial of on the job exposure, came the claim that some people may have had a history of illicit drug use, sexual promiscuity, or other stigmatized behaviors. The city government tried to alienate this group from mainstream culture and segregate them based not only on the fact that they had hepatitis C, but also that they were most likely involved in particular stigmatized behaviors.
Fire Fighter’s Union

To counter the position of the city, the union relied on a characterization of the disease that differed from the typical biomedical conceptions. It was not a set of symptoms and a pathological entity. It was impacting and affecting the lives of people, just like it could affect the lives of you or me. The union and its members with hepatitis C tried to identify with other people to show that diseases could not just be diagnosed and then the person left to suffer. This was something that required a collective recognition of the problems and subsequent actions to do the best thing for those people afflicted with HCV. The union defined health as being not only free from physical symptoms, but also having happiness, social support, and equal treatment. Hepatitis C moved from the category of disease, to that of illness because there was the acknowledgement of individual perception and experience in relation to testing positive for HCV.

Of course, coming from the fire fighters’ perspective, the coverage of the issue on their website is biased. Because of the success of the union and the passing of legislation the stories of Mary Kohler and the entire union serves as inspiration and is a success story that the union would want to cover. By giving links to outside sources, the union is increasing the likelihood that the members will read more about what is available to the scientific community. Access to this information is crucial so that one can understand a diagnosis of hepatitis C in relation to biomedical treatment. However, by framing hepatitis C with the biomedical perspective and giving a voice to those members afflicted with the disease, the union has moved outside of a solitary discourse creating new arenas for voices to be heard. They are not speaking for the city. Since they are able to speak for themselves through this medium, they are able to present their
perception of the problems. The city can not speak through this site, but does have the ability to cover the same issues on their own site.

A search on the city’s websites did not turn up information regarding hepatitis C as explicitly as Local 22’s website. The absence of information is important for the silencing of an issue, can take just as much effort as the publicizing of it. By not supplying information on the topic, the city is able to ignore the issue to a certain degree and shows that it does not see the need to take an official stance in the medium being used as a powerful force by the fire fighters. The one mention is in a Transitions Workforce committee report, in which Street’s initial allocation of money is praised, but says there is room for some improvement (http://www.phila.gov/transition/cityworkforce.htm: March 2002).

The union was the collective entity the fire fighters needed to assert their concerns. This was the group with power that could counter the claims of the city. It worked for its members, because it was much more involved in the personal lives of these people. The city was responsible under their claims because of the fact that the fire fighters were working for the city. Without the work of first responders, the city would not be able to claim to offer services of protection. By serving the city, these men and women saw the city as an authority that had to take action. However, they were able to contest the authority of the city because of their ability to harm the city in the eyes of its other citizens. The union was able to portray the way in which having hepatitis C hindered their ability to perform their jobs. Without treatment, these men and women no longer can be the civil servants, on which many people rely.

On the international level, the IAFF also backed the continuation of the scientific study of hepatitis C in relation to emergency responders. This is interesting because of the lack of evidence that such research has presented in favor of first responders in the past. I see the IAFF
as wanting there to be government researchers because of its recognition of the authority and legitimacy that the public would connect with information for those sources.

Working with the knowledge that Pennsylvania state law covered other people exposed to blood on the job, the fire fighters used the tactic of normalizing or generalizing the laws. They could raise these discrepancies in addition to the fact that other states, and cities covered fire fighters for exposure to blood borne pathogens. Philadelphia became the one city that was not willing to protect the people they employed. This in turn could be extended to the general public. If the city was not going to help its own workers, what would it do for its citizens?

Calling upon the city to pay for compensation benefits could even be seen as a positive for other citizens when coming from the fire fighters union. The gesture of possible collective responsibility created a connection among the civil servants, the city, and the people, to which both groups were responsible. There could be the creation of a social bond of support and respect. The people would not be paying for just health coverage for this one disease, but helping a fellow human being who could in turn help them and others. The fire fighters could criticize the economic model advanced by the city, because they had the support of fellow citizens. Health was not going to be something that was only accessible in certain situations. The union had to recognize that in the current system it required money, but it was more an issue of equality and access to the possibility for health and well-being than a struggle for economic gains.

The dichotomy between a bureaucratic institution and a group of citizens is clear, and how the system is unwilling to take care of its members. The union stands in contrast to the city as a collective, for this is the group that listens to its members and works for change. This was a joint fight for equality and the protection of human rights, most specifically for personal health.
The union emphasized personal ties, so those individuals were made to feel like people who were cared about by others within the social network of the union.

**State of Pennsylvania**

At the level of the state, the fire fighters found support that they were unable to elicit from Mayor Street and the city government. Citing the obvious, that other states had coverage for hepatitis C, legislation was passed quickly. A discourse of morality emerged and the state placed itself as responsible for protecting its people. The divide between the city and state is interesting because they are both dominated by and participants in the capitalist economic and political arenas. However, perhaps the distance of the state from the other financial concerns within Philadelphia, lessened the economic concerns and the legislators supported the bill for the protection it afforded and the message it sent to its workers and citizens. Also, if the money came from each municipality, the state would not suffer direct financial repercussions. The state was able to take on a humanistic role and position itself in positive light for its citizens and nationally. Safety is coming before money.

Ultimately, the fire fighters were needed to uphold part of society and the cultural norms of United States cities. They were a part of the system and the loss or alienation of this group would threaten the position of the existing institutional norms. In order for there not to be questions and contestations concerning existing structures and practices, this may have been an important move to quiet a powerful voice. Even with the possibility of alternate motives, the benefits that this measure had for the fire fighters can not be overlooked.
Role of the Union

Development of Unions

Local 22 of Philadelphia Fire Fighters’ Union was met with a health problem that they were able to address and enacted changes for the benefit of their members. What interests me most, is the unique and powerful position of the union in this situation. Capitalism flourishes using subordination and authority. To be liberated, one must no longer be or feel a dependence on the group in control (Lodziak 1995:94). In order to create an alternate system of beliefs and ideas and in a sense a culture, one must have the agency and the resources to do so (Lodziak 1995:98). However, culture implies a group or collective and so an overcoming of the individualist ideology is also a necessary step. Unions stand in the unique position to accomplish this goal of self-realization and empowerment (Lodziak 1995:112). A union is the autonomous form based on cooperation and association that can enact change. By expanding and engaging with a larger public, the sphere of autonomy has the chance to grow and the potential for action and change increases (Lodziak 1995:113).

The belief that civil society exists to this degree, in the United States, can be seen as important in the development of unions. The notion of association separate from the political organization is essential for the development of labor unions and the voice of the people in other groups not directly connected to the state. In the sense that this is where the macro social guarantees are expressed as interests, civil society is the place where policies and actions can be questioned and challenged to ensure that they work equally for all people involved.

Many of the health demands and consequent changes in policy have resulted from the movements in the labor sector (Navarro 1993:85). When threats arise from the producers, it is
necessary to acquiesce to certain demands or else participation in the market will be impossible. There are constant struggles and demands for better coverage and programs, including, universal health benefits, participation in the directing of the health care system, and government responsibility (Navarro 1993:85). In 1992, 17% of the population had no health benefits (Navarro 1993:15). The United States and South African governments remain the only major countries not to provide national health care programs to their citizens.

Although not explicitly characterized as marginal, in the context of the economy, workers are differentiated from the capitalists. The interests of the workers must be fought for because of the hierarchical nature of the economy. The AFL-CIO and other unions are the publics that defined and work for the macro social guarantees of freedom, equality, and representation for workers.

Identity and the Union

Erickson asserts there can be “no meaningful identity if it is not anchored to a group setting” (Lodziak 1995:82). The role of the union was so important because it created an identity not only as a group but also an identity for the individual fire fighters. “Specific, often socially powerful, cultural discourses and practices both position people and provide them with the resources to respond to the problematic situations in which they find themselves” (Holland et al. 1998:32). The union created a position from which the fire fighters learned discourses and practices that could be used to fight for what they wanted. The very fact that fire fighters were describing what could be done to educate using the union information, showed that they were associating themselves as belonging to the group from which that knowledge originated (Holland et al. 1998:135).
The actions of the union also made it a site for identity as “action is the social expression of identity” (Breakwell 1986:43). Creating a group that was actively engaged with a problem, gave the fire fighters the chance to align themselves and identify with the actions if they were in support of them. Taking part in a protest outside of City Hall, makes one clearly see themselves as part of a group. The union in fact could create a whole new belief system that if held would indicate membership (Breakwell 1986:39). Identifying the threat that hepatitis C posed, the union became a group that could construct a new identity of strength and action for the fire fighters. It was an incentive to work for change when the fire fighters had the support of each other and larger national and international unions. By taking part in this social movement, which was an effort to solve a problem collectively that the fire fighters felt they had in common, the union could “attribute positive value to the group” (Breakwell 1986:138) and to the individual fire fighters, by investing them with a sense of power.

Voice and Power of the Union – A “Strong Public”

By Fraser’s analysis, the position of the union would fall under the categorization of a “strong public” (Fraser 1996:134). This group’s abilities encompassed opinion formation along with decision making. Unions create collectivities of people who might otherwise not recognize that others share their concerns. In bringing people together, there is the creation of discourse and a place to discover interests. This is an organization that creates small communities whose boundaries are not defined by state or national institutions of the government. New arenas give people a voice and with a multitude of people, the union can be a center of power to advance change.
The institutions which embody the ideals of the system are also the sites “for the construction of consent that defines the new, hegemonic mode of domination” (Fraser, 1996:117). Biomedicine and then in a certain sense, the profession of the fire fighter, fit into the mainstream societal ideas. However, the fire fighters raised concerns over the actions of the city, a mainstream institution. The fact that the fire fighters contested the norms of the system, which they were also embodying, shows the role of the public sphere in contrast to the state. This arena gave these individuals and the group of which they were a part, the opportunity to speak out and work for change. The fire fighters and more specifically the union knew how to work within the already existing institutions to realize their goals, appealing to the state Legislature, the media, and the general public, the citizens of Philadelphia.

The “counterpublic” of the fire fighters and the union was in opposition to the state, yet is also a parallel arena where they could “invent and circulate counterdiscourses to formulate oppositional interpretations of their identities, interests, and needs” (Fraser 1996:123). The fire fighters helped to expand “discursive space” and this undertaking extended that space to others audiences. The fire fighters brought this to the attention of new groups, working to have an understanding and realization of the ideals of a truly plural, democratic society. Habermas notes the important sense that publics have of being involved in a potential wider public at any given time (Fraser 1996:124). This can be a motivation for action. As fire fighters, citizens, family members, friends, and patients, this group of people could make multiple identifications and see various positive outcomes for their undertaking.

This was an attack on the hegemony of the system from an inside position. This internal contestation, may be in part why change was successful and visible in the larger sphere. This “counterpublic” included some of the ideals of those they were opposing, but because of the
reliance of the greater public on this group of people, the fire fighters had an even greater influence and degree of power. The fact remains that the United States is a stratified society and so, the position of these people in the hierarchy placed them as participants in the institutions, which they did not necessarily support on all grounds. In such a society, the “basic institutional framework generates unequal social groups in structural relations of dominance and subordination” (Fraser 1996:112). This group had to fight for to realize their ideals of equal representation, health, and happiness.

CONCLUSION

Looking at an illness, one is “implicated into a vortex of competing discourses” each having claims, interests, and politics (Krug 1995:300). There is a void concerning the ramifications of this disease because of its relative new entrance into the medical realm and its influence on social, cultural and personal aspects of life. Hepatitis C came into the public sphere in the form it did in Philadelphia, because of the movement by Philadelphia’s fire fighters to get the disease recognized as an on the job health risk. Public interest anthropology applied to the issue of Hepatitis C among Philadelphia fire fighters can best be seen within the framework of identifying the interests of this particular public. It is extremely important to pay special attention to this issue because of the ways in which hepatitis C affects one’s health. This issue exists in a diverse society, which has been marked by inequalities extending into the arenas of personal health, well being, and quality of life.
This research addressed the amount of knowledge that existed concerning hepatitis C and its impact on one’s life. Hepatitis C is of great concern to not only the Philadelphia fire fighters, but also many other groups and individuals. To understand this one situation, with an eye on the cultural and historical practices that influence people’s perceptions, actions, emotions, and beliefs, sheds light on similar situations and increases the knowledge available to the general public. There can be an “advancing of knowledge through attention to the ‘dilemmas’ and ‘perplexities’ of our time as defined by groups of people or whole societies” (Sanday 1998:3).

The union’s description of hepatitis C and its impact on the public, the city and the state was essential to achieving the goals of additional health coverage for fire fighters. This group stood in a unique position for they were participants in society very directly in their role as civil servants, yet they contested the city and state laws and enacted changes. The union provided information, knowledge, support, and guidance for its member, thereby helping to construct the model of hepatitis C. This was a model that would help the fire fighters to realize their goals. A life-threatening situation became the impetus for collective action, a solidification of union morale and support, and the voicing of opinions. The union’s model of hepatitis C made it a personal illness. The union listened to and supported its members, fighting the injustice that they perceived, by constructing a model of hepatitis C embodying self-realized power, knowledge, and action.
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New Haven County Liver Study – Days of Physical and Mental Ill Health

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Table 1: Data from the New Haven County Liver Study. Number of days of physical or mental ill Health over a 30-day time period with p values.
Global prevalence of Hepatitis C
Based on published data, update 1999


84
Figure 2: Hepatitis C positive serologies in Philadelphia 1998-2000, reported by age group and gender (after City of Philadelphia Department of Public Health 2001:8).
Figure 3: New Haven County Liver Study – Distribution of Chronic Liver Disease Etiologies, non-HCV versus HCV.
Days of Physical and Mental Ill Health over 30-Day Time Period
New Haven County Liver Study

![Bar chart showing days of physical and mental ill health over a 30-day time period, comparing people with HCV to those with CLD (not HCV).]

Figure 4: New Haven County Liver Study - Days of Physical and Mental Ill Health over a 30-day time period, HCV versus non-HCV.
Figure 5: New Haven County Liver Study - Education and Income for HCV versus non-HCV
Figure 6: New Haven County Liver Study – Drug and Alcohol History of HCV versus non-HCV.
Prevalence Rate in United States and Philadelphia Fire Fighters

Figure 7: Hepatitis C Prevalence in United States and Philadelphia Fire Fighters.
Dear Participant,

Very little is known regarding Hepatitis C, yet within the United States, there are an estimated 2.7 million people infected with Hepatitis C. I am interested in the ways that people with Hepatitis C and people with knowledge of Hepatitis C think about this infection. As an anthropology student at the University of Pennsylvania, I feel it is very important to learn more about Hepatitis C, as it is one of the issues of great concern to the Philadelphia community.

Your participation will assist me in completing my senior year research project. Please return this in the accompanying envelope as soon as possible.

Everyone may answer the first set of questions (1-12). The second set is for only those people with Hepatitis C. All information is being obtained anonymously. You do not need to answer any questions that make you feel uncomfortable. If you don’t want to answer any of the questions or if a question doesn’t apply to you, just mark NA (for not applicable).

I greatly appreciate your timely response. Thank you for your help.

Leah Ferrucci
leahf@sas.upenn.edu
Department of Anthropology
University of Pennsylvania

1. How long have you worked for the city of Philadelphia as a firefighter? Were you a firefighter anywhere else?
2. How long have you been a member of the Philadelphia Firefighters Local Union 22?
3. Why did you decide to become a firefighter?
4. Have you always lived in Philadelphia?
5. Did you know anything about Hepatitis C before it came out that other firefighters had it? If yes, what did you know?
6. How did you first hear about Hepatitis C?
7. Do you worry about getting Hepatitis C on the job?
8. Tell me what you think it is like to have Hepatitis C? Do you think it is the same for everybody who has it? How did you learn this information about Hepatitis C?
9. What have the city officials done to address firefighters’ concerns about Hepatitis C? What else needs to be done so that people feel satisfied?
10. Do you think that the general public knows enough about hepatitis C?

Continued on back
11. What else should the public know about it?
12. What should be done to prevent the spread of this disease?

The following questions are for those people with Hepatitis C.

13. When did you learn you had Hepatitis C?
14. Who else besides you (and your doctor / medical professionals) knows about your condition?
15. Are you married? How has the illness affected your relationship with your wife/husband? If not married, do you have a boyfriend/girlfriend? How has the illness affected your relationship with your boyfriend/girlfriend?
16. How has your illness affected your relationships with your friends?
17. Do you have any children? If so what are their ages?
18. How has your illness affected your relationship with your children?
19. How much of the time during the past two weeks have you worried about the impact your Hepatitis has had on your family? Would you say that this is different from when you were first diagnosed and how is it different?
20. How has your illness affected your relationships with your co-workers?
21. Do you have someone you can count on to take you to the doctor if you need a ride?
22. Do you have somebody you can talk to about how you feel about being sick?
23. If yes, to above two questions (21 & 22), what would it be like if you didn’t have these people to depend on?
24. Does anyone treat you differently since you found out you had Hepatitis C? What is it like?
25. Would you say your health in general is excellent, very good, good, fair, or poor?
26. During the past 30 days, for about how many days did your health keep you from doing your usual activities, such as self-care, work or recreation?
27. Thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days, was your physical health not good?
28. Compared to a year ago, how would you rate your health in general now:

(Check one) .................................................................................................................. Much better than a year ago ___
   Somewhat better than a year ago ___
   About the same as a year ago ___
   Somewhat worse than a year ago ___
   Much worse than a year ago ___
29. Thinking about your mental health, which includes stress, depression and problems with emotions, for how many days during the past 30 days was your mental health not good?

30. During the past 30 days, for about how many days did poor mental health keep you from doing your usual activities, such as self-care, work or recreation?

**For questions 31-35, please circle the answer which best matches how you feel.**

31. How often during the last two weeks have you felt anxious?

   - All of the time
   - Most of the time
   - A good bit of the time
   - Some of the time
   - A little of the time
   - Hardly any of the time
   - None of the time

32. How much of the time during the last two weeks have you had problems concentrating?

   - All of the time
   - Most of the time
   - A good bit of the time
   - Some of the time
   - A little of the time
   - Hardly any of the time
   - None of the time

33. How much of the time during the last two weeks have you felt unhappy?

   - All of the time
   - Most of the time
   - A good bit of the time
   - Some of the time
   - A little of the time
   - Hardly any of the time
   - None of the time

34. How much of the time during the last two weeks have you worried about your condition getting worse?

   - All of the time
   - Most of the time
   - A good bit of the time
   - Some of the time
   - A little of the time
   - Hardly any of the time
   - None of the time

35. How much of the time during the last two weeks have you worried about never feeling any better?

   - All of the time
   - Most of the time
   - A good bit of the time
   - Some of the time
   - A little of the time
   - Hardly any of the time
   - None of the time

36. In what ways has your job training and experience as a firefighter helped you to cope with the diagnosis of Hepatitis C?

37. Are you a military/armed forces veteran? If so, have any of those experiences helped you to handle the current situation you face as a person with a chronic disease?

38. What other life experiences have helped you to cope with having Hepatitis C?
39. Are you getting treatment for your condition? If so, is it in Philadelphia?
40. Please describe your interactions with the medical community. What kinds of information and support have they provided you with?
41. What, if any, alternative or complementary medical treatments (such as reiki, acupuncture, acupressure, massage, herbalist, etc) are you using/or have used?
42. Who or what else has helped you with your disease? (These might include religious groups, community centers, disease support groups, exercise, meditation etc.)
43. Was the term “chronic” used when your diagnosis was made? How did this make you feel?
44. In what ways do the financial aspects of having Hepatitis C influence you? Are you concerned about a financial debt because of treatment? Are you concerned about not being able to work?