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# "Constructing" Hepatitis C in Philadelphia

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# "Constructing" Hepatitis C in Philadelphia

## **Abstract**

This research explores how the CDC Hepatitis Epidemiology Investigation Team at the Philadelphia Department of Public Health (PDPH) constructs Hepatitis C (HCV) in the public and medical discourse through their monitoring and education activities. Data in the form of field notes and ethnographic observation was collected during 16 months of participant observations at the Philadelphia Department of Public Health. This research provides evidence that the team's actions give voice to a silent epidemic by being responsible for the construction of the conversations happening around HCV in Philadelphia. Their actions in the domains of risk factors, support systems, public health and prevention, stigmatized behaviors and safe practices, bodily proof and silent epidemics, health insurance, and medical hierarchy will ultimately determine the future climate of hepatitis in Philadelphia. This research can serve as insight into the functioning of public health teams and how more positive and proactive conversations surrounding diseases can be instigated.

## **Disciplines**

Anthropology

“CONSTRUCTING” HEPATITIS C IN PHILADELPHIA

By

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Thesis Advisor: Dr. Adriana Petryna

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This research explores how the CDC Hepatitis Epidemiology Investigation Team at the Philadelphia Department of Public Health (PDPH) constructs Hepatitis C (HCV) in the public and medical discourse through their monitoring and education activities. Data in the form of field notes and ethnographic observation was collected during 16 months of participant observations at the Philadelphia Department of Public Health. This research provides evidence that the team's actions give voice to a silent epidemic by being responsible for the construction of the conversations happening around HCV in Philadelphia. Their actions in the domains of risk factors, support systems, public health and prevention, stigmatized behaviors and safe practices, bodily proof and silent epidemics, health insurance, and medical hierarchy will ultimately determine the future climate of hepatitis in Philadelphia. This research can serve as insight into the functioning of public health teams and how more positive and proactive conversations surrounding diseases can be instigated.

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## **Acknowledgements**

I would like to thank the Philadelphia Department of Public Health for allowing me to be a part of the CDC Hepatitis Investigation Team for a year and a half. It has been an adventure learning about hepatitis and approaches in public health. The warm office environment and encouraging team were essential to the success of this research. I would also like to thank my thesis advisor Dr. Adriana Petryna whose courses and insights into ethnographic research, the study of science and understanding the contexts in which diseases exist were invaluable to this research.

## **Introduction**

I would like to preface this piece by putting forth that it is not an investigation into how a disease is conceptualized by the population burdened by it as we so often do within medical anthropology. There were no interviews with patients on their perceptions of their illnesses. It is also not an evaluation of a public health intervention with an anthropological critique to improve effectiveness. This paper is an investigation into how one team operationalizes a disease in their research. The research serves as an ethnographic snapshot into how a group of health scientists perform their work and what that work means to the greater community.

Hepatitis has often been referred to as a “silent epidemic (Chen, 2002).” This label highlights the fact that the viruses that cause hepatitis A, B, C, D and E are not part of the public discourse of disease. The risk factors, methods of prevention, methods of transmission, and treatment are not common knowledge contributing to its status as a “silent epidemic.” As seen with many other diseases, without conversation, action is not taken (Yamey, 2002). The CDC decided to spark the conversation about hepatitis in the United States when in 2013 it granted 5 cities the ability to expand their hepatitis surveillance.

While the CDC’s expectations were data collection in order to further understand the true impact of hepatitis, there have been many other impacts in Philadelphia with the implementation of this grant. This research investigation did not originally set out to identify how researchers create a new space for the discussion and public discourse of HCV, but rather to understand more broadly the burden of HCV in Philadelphia. Through observation a trend emerged that influenced the way in which findings are presented in this paper. In the hepatitis team’s efforts to gather data, I began to notice domains in which they a created a space for discussion. Whether

that discussion is positive or negative will be played out in the coming years and presents itself as the future trajectory of this research.

In order to better understand the point of this research and the impact of the team on this ambiguous “culture of hepatitis” in the city, I call upon the example of HIV/AIDS. When HIV/AIDS entered the public discourse it was met with social stigmas surrounding homosexuals and later race, tainting the space it occupied as negative (Harris, 2009). This negative conversation impacted everything from support systems to insurances statuses. We can contrast this disease space with that of breast cancer which has a far more positive public discourse surrounding it. How the hepatitis team operates, what they emphasize and highlight, and who they interact with all create the space in which hepatitis can be constructed, understood, and lived in Philadelphia. The domains selected for observation in this paper are risk factors, systems of support, public health and prevention, stigmatized behaviors and safe practices, bodily proof and silent epidemics, health insurance, and medical hierarchy. A deeper delve into the team’s actions in each of these areas will provide a further understanding of the construction of the aforementioned “space.”

## **Background: Significance of Hepatitis C as a Global “Silent Epidemic”**

### **HCV as a Global Burden**

Viral hepatitis is a growing global concern as prevalence and mortality rates continue to rise and many worry it will be a pandemic that will possibly overtake HIV (Morris, 2013). With the introduction of the new drug regimens and the patterned stigmatization attached to Hepatitis C (HCV) transmission, which mirrors that of HIV, it is possible that we may be able to do for hepatitis what we have done for HIV. In 2010, there were 1.4 million deaths from Hepatitis B (HBV) and C, a number just shy of the number killed by HIV (Morris, 2013). Hepatitis, in all its viral forms combined, is the 8<sup>th</sup> leading cause of death worldwide. In Asia, the combined infection rates for HBV and HCV are greater than 20%, only further substantiating the claim that HCV is a significant health burden (Morris, 2013).

### **HCV and Global Public Health Programming**

HCV has been ignored by many of the global leaders in public health. The United Nations Millennium Development Goals’ focus has left HCV to be considered mainly as a co-infection with HIV, not as its own illness. This lack of visibility leads to a lack of funding. For example, Mongolia and Vietnam have HBV and HCV rates as high as 20% and HIV infection rates less than 0.5%, yet they have dedicated staff and programs for HIV, but not hepatitis (Morris, 2013). The World Health Organization (WHO) regional office for the Americas was even on the verge of dropping hepatitis from their 2014-2019 strategy due to lack of funding. However, there are those offering solutions. The Global Commission on Drug Policy has called to divert resources from the war on drugs and other drug policies to fuel HCV treatment (Morris, 2013). This is a fitting proposal considering a common means of

transmission of HCV is through injection drug use (IDU). Despite clear knowledge of this fact, on the local level within the State of Pennsylvania, needle exchange programs are considered an illegal operation due to “encouraging drug use.” If less time and money was put into fighting drug use and rather approaching it as a public health concern, HCV transmission rates could be greatly reduced.

### **Domestic HCV Situation**

Within the United States it is difficult to estimate the number of people with chronic HCV infection. Not everyone who would qualify for therapy has been tested and identified, referred for appropriate care, and offered or given the best therapy available (Holmberg, et al, 2013). There are an estimated 3.2 million people in the US with chronic HCV infections, of that 1.6 million (50%) had HCV detected through testing and of those people, 1.0-1.2 million (32-38%) were referred to care. Of those who have been referred to care, only 220,000-360,000 (7-11%) were treated and of those treated 170,000-200,000 (5-6%) were successful in their treatment (Holmberg, et al, 2013). In order to address increased testing the Centers for Disease Control and Prevention (CDC) recommends a one-time test for everyone born between 1945 and 1965 to help identify people who would not be normally targeted (an age cohort). The CDC has also been releasing large grants to improve the monitoring and surveillance of hepatitis in order to better assess the status in the United States. One of these grants is the focus of this paper. The most common risk factors for the contraction of HCV include IDU, tattooing, and men who have sex with men (MSM). Many people are unaware that they need to be tested because they have none of these risk factors, however, before 1991, blood transfusions were not screened for HCV and many people obtained the infection in this

way (Holmberg, et al, 2013). Based on the previously stated data, it is right to deduce that within the United States, there is a silent epidemic of viral hepatitis.

### **Hepatitis Interventions**

The most positive developments in the field of hepatitis are in the work of immunization campaigns for HBV. Unfortunately, no vaccine exists for HCV and prototypes are, at best, at the preclinical phases of development (Morris, 2013). For this reason, the most effective steps that can be taken towards reducing HCV rates are in the area of treatment; those who are cured can no longer transmit the virus. Protease inhibitors, a class of drugs which prevent viral replication, such as tenofovir, boceprevir, and taleprevir have already transformed chronic hepatitis management and in the next 2-5 years, 90% of HCV infections will be curable with a once-daily, 12 week, low toxicity, oral regimen (Morris, 2013). Other countries have already proven the successfulness of integrated testing campaigns – something not seen in Philadelphia. The United Kingdom predicts that with their aggressive testing and treatment programs they can eradicate HCV by December 2027 (Morris, 2013). Yet no initiatives on such a massive and integrated scale have been proposed in the United States, on the national, state or city level.

HCV is coming upon a revolution: New drugs are about to enter the market and change the way in which patients and doctors think about treatment. A major barrier facing the implementation of these new drugs is the enormous cost. A course of treatment will cost between \$60,000 and \$100,000 (Holmberg, et al, 2013). Under the Affordable Care Act (ACA), states had the option to expand their Medicare and Medicaid packages; however, some states chose to not opt in. Pennsylvania is one of those states. There has yet to be research on

what this means to the future of HCV treatment, especially considering the demographics of who carries the largest burden of the disease, which still requires further exploration in across the United States. In order to properly address treatment and prevention gaps in hepatitis, a greater emphasis needs to be placed on understanding the medical system and public discourse of hepatitis as a whole.

## **Methodology**

In order to answer the queries posed in the introduction, the research method selected was the use of ethnography. Qualitative data was collected through participant observation that lasted the duration of 16 months, averaging 10 hours a week in the field. Ethnographic data provides the opportunity for careful the daily, inner-workings of the Hepatitis Team. Quantitative data on hepatitis statistics and team productivity or short-term field work would not be able to comprehend the nuances of team interactions. This form of data collection allowed a thorough development of relationships with the subjects of interest to see how operations go in a natural environment. Data collected through this means was done via handwritten field notes that were later typed for analysis. The field notes were then analyzed using nVivo software so as to identify themes and trends.

I gained entry to the PDPH and the hepatitis team through a previous relationship as an assistant to the team and the Division of Disease Control. This relationship gained me access to both the team and the other groups that they interact with, mainly HepCAP and Prevention Point. Interviews were excluded from the methods per the subjects' request so all data was dependent on participant observation. The exclusion of one-on-one interview did not affect the research as much as anticipated due to the nature of the research observing how the team interacts with their work, not necessarily looking too deeply at what they have to say about their jobs. Most information that would have come from interviews came out natural through informal conversations and through my attendance at weekly meetings. Necessary context information was gained through the long duration spent in the field. Ethnography ultimately allowed for the exploration of this team in a more flexible way as opposed to a pre-set, rigid methodology set on testing a specific hypothesis (Hahn, 1999).

## Results

### The Field Site

The field site was the Philadelphia Department of Public Health, Health Center #1 at 500 S. Broad Street along Avenue of the Arts in Downtown Philadelphia. The building is an old theater built of green bricks transformed into a sea of cubicles. The building smells of the lab on the upper floor. The office is fairly noisy due to the acoustics of the sourcing ceiling that once served to project performances. While the maze of cubicles seems hectic at first, it is an organized chaos of teams and departments. My observations began the fall of 2013 and ran through March of 2015 with time off during the summer months for a total of 16 months, averaging 10 hours a week. Observation time was split between assisting in data entry and attending to my personal research.

The spaces within the site that provided observations were the Hepatitis Investigators' (Hepi's) cubicle section, the Division of Disease Control central desk unit, Board Room 1 where weekly meetings occurred, Board Room 3 where meetings with the entire DDC group took place, the building auditorium where HepCAP support group meetings took place every other Wednesday night, and at Prevention Point in North Philadelphia.

The PDPH is first and foremost a place of science. Scientific method and means of evaluation and quantification are in everything that is done. It is therefore important to understand that in this field site, hepatitis C is understood as a biological conditional caused by a viral infection of the liver. There are no other acceptable explanations to this team as their work is based off a belief in this as an absolute fact. With other medical anthropology field sites, an investigation into how the population perceives their bodies and the causes of their disease is

necessary, however, this site is clear with a Western biomedical model of understanding (Scheper-Hughes and Lock, 2009).

## **The Grant**

In May 2013, the Philadelphia Department of Public Health announced to greater Philadelphia that they would be doing increased surveillance of hepatitis (Figure 1). This announcement followed the receiving of a large CDC grant to the PDPH to collect further metrics on the epidemiology of hepatitis. The PDPH had to make adjustments within its Division of Disease Control to accommodate the additional staff, but the prestige and size of the grant was enough motivation to expand as necessary. The investigation team even received a brand new cubicle room complete with a door and new chairs. When I joined the field site, the grant's activities had been underway for only four months. Upon completion of my research, they were only halfway through the grant duration of five years. Data and surveillance will still be ongoing until 2018.

The grant deserves to be mentioned in its own section because of the significance that grants of this kind have in influencing the disease conversation. This grant could have easily been about any other disease and hepatitis would not have had its time to prove its importance in the public discourse. Timing and influence of new pharmaceuticals about to come to market as likely put some pressure for increased surveillance (Pawlotsky, 2014). The grant's focus was surveillance, but it also included an education component that required the team to disseminate information to both patients and providers. The structuring of the grant to include a section on education is also important to the power inferred to the team to influence the conversation around HCV.

## **The Team**

There are 7 people at the PDPH on the hepatitis team. The team is made up of a director (PhD), epidemiologist (MA), education outreach (MA), web and materials designer (BA), and 3 hepatitis investigators (BA's). The blending of degrees and expertise creates a well balanced team that is not too heavy in any one particular perspective or field of study. Public health often draws from various degrees and levels of professionals to achieve its results valuing the different experiences each individual has to offer.

Kendra, in her role as director, overlooks all activities while troubleshooting problems. Danica is the epidemiologist whose job it is to assemble the data into reports and statistics to monitor program advancement and report back to the CDC. Erin, the education outreach position, works directly with the web and materials designer and has limited interaction with the rest of the team. The web and materials designer, Evan, is the only male on the team and the newest addition. His job is to produce the educational materials and design the new website. Finally, there are the 3 female hepatitis investigators or "Hepis (Hep-ees)" who performed the bulk of the work in data collection and have direct patient and doctor interaction. The Hepis and their work are the main focus of my research since they have the most influence over how the program is played out and how relationships with providers and patients are developed.

The team works in two separate parts of the field site with Hepis seated in one cubicle section and the rest in a different office. This separation established a hierarchy between the two parts of the team divided by degrees and age. The team meets every Wednesday morning for an hour to discuss Hepi investigations and trouble-shoot problems. Every other Friday they get together for a two hour meeting that involves a time to catch up on the most recent literature in

the subject area, discuss upcoming presentations at universities or health centers, and strategize long-term program goals.

The Hepis are fresh college graduates working their way towards grad school or enrolled concurrently. Their responsibility is to make phone calls to patients and doctors to ask a schedule of questions that determine the point of infection as well as ask general demographic information. This sometimes involves doing home or office visits to audit records or track down patients. They also flag cases that are unusual or should be under close monitoring. These cases include pregnant mothers, acute HBV cases, and cases of re-infection. They report directly to the epidemiologist and utilize the director as a means to troubleshoot noncompliant doctors or difficult patients. At the start of the program, each Hepi had a different take on the research at hand. While some took the intimate phone call interviews with a grain of salt, others were deeply affected by the conversations when patients or physicians reacted negatively. By the end of the first year, they had all become hardened veterans. They also began to create their own ideas for education and survey questions including the translation of patient letters and asking patients about their health insurance status.

Looking at the motives for each person's involvement on the team lends insight into the way in which public health operates. For Danica and Kendra, both specialized in infectious disease, working on a hepatitis project was something they always wanted to do. The education outreach coordinator had personal experience with gay friends who had been affected by HCV and took the job coming from previous work with the HepCAP support group. The materials designer had transferable skills and took the job because it was what was available. Motives for Hepis being a part of the team were split. Two Hepis had no hesitation in stating that they were a part of the team because they needed it on their resumes for graduate school. The other, a Penn

graduate of 2013 and Health and Societies major said she was curious and having never given much thought to hepatitis before. Given her education and background, her lack of knowledge on hepatitis serves as further evidence for the overall absence of conversation surrounding the disease. Despite individual motives, there universally appeared to be a strong desire to create an impact. This was evidenced to me by the team's enthusiastic involvement in their testing of people at the local needle exchange program (NEP), Prevention Point. They all went through phlebotomy training to learn how to draw blood and take turns every Friday testing patients and conducting interviews in person.

## **The Work**

The work of the team can be divided into 3 main categories: Patient and provider investigations, patient and public education, and data analysis. Each part plays an important role in the overall completion of the program with various members of the team working on different parts.

Investigations are the domain of the Hepis. This is the point of contact with providers and patients and serves as primary data collection. Newly reported cases to the PDPH are sorted by Danica and then "pushed" on the Communicable Disease Management System to the Hepis based on the zip code in which the patient resides. This means the file for the patient is electronically sent to a personalized workflow for the Hepi to access. Each Hepi has their own set of zip codes they are responsible for with an even distribution of low prevalence and high prevalence zones. Hepis then send a letter to the patient and their provider warning them of an upcoming interview. This gives the recipients the opportunity to call the Hepis first or wait for a Hepi to reach out to them in the next few days. About half of the time the patient will call first

having been alarmed by the letter they received in the mail. Once the patient calls, the Hapi will ask them to participate in important data collection for the CDC to help understand how people contract hepatitis in Philadelphia. Most patients comply with an interview while some do choose to opt out. The standard survey includes demographics, medical history, risk factor questions, and questions about treatment and interactions with their physician averaging about 10-15 minutes. The provider schedule of interview questions is the same as the patient's, however, provider calls prove to be the largest obstacle faced by the Hapi team. There is more on why this is a challenge for the Hapis that will be discussed in detail in the Medical Hierarchy subsect of the Discussion section.

The Hapis incorporate education opportunities into the interviews. At the end of interviews, Hapis ask if the patient or doctor's office would like to receive additional materials on hepatitis. This is just one of the elements of the education and outreach component of the grant. There is also education outreach through partnership with the local HepCAP support group where the team makes frequent presentations and disseminates educational materials. For the work done at the local needle exchange program (NEP) Prevention Point, there are materials specifically designed for this transient population. These materials include discreet appointment cards and education cards that fit into a wallet. The need for wallet-sized education materials that were focused on compliance came from observation of the population at the NEP and their specific needs. The education team is also responsible for the creation of the website to educate the Philadelphia public about hepatitis. This project is nearing completion and has not gone live yet. The interpretation of education intervention as stipulated by the grant is loose and this component tends to be created as needs are seen in the community.

The final component of the work done by the team is compiling the data for analysis by the epidemiologist. Danica's entire job is focused around running reports and creating statistics for the CDC. While the least exciting role to execute, Danica's data analysis is the fruit of all the team's labors. Due to competition with the New York City Department of Health, I was unable to use any of the data gathered by the program for this paper. The team has not officially published any of the findings and considers themselves in direct competition with NYC for the best hepatitis surveillance in the country. They did not want to risk their data being leaked to the NYC department.

## **Discussion: Constructing the Conversations**

In observing the daily activities of the hepatitis team, their actions and the impacts of those actions began to emerge as a theme. The results of their interventions extend beyond the gathering of data and are constructing the atmosphere in Philadelphia surrounding the diagnosis, treatment, and prevention of HCV. The realms of influence that the team is instigating conversation and change in are discussed throughout the rest of this section. For an abbreviated illustration of the information, please refer to Table 1.

### **Around Risk Factors**

A frequently faced challenge of the team involved the identification of infection through risk factors. This challenge originated not because the means of identification of infection are difficult, but rather because questions about risk factors are laden with social stigma. When a question makes the patient uncomfortable, despite anonymity, they are less likely to respond. The hepatitis team frequently faces apprehension from patients with the questions involving such topics as sexual history, drug use, and other social activities such as tattooing. Lack of response on these questions leaves gaps of knowledge in understanding the hepatitis landscape in Philadelphia. In order to prevent infections, the team must know where they originate from.

At a Wednesday morning meeting in early fall of 2013, only 4 months after starting the program, the issue of data collection on risk factors from unwilling participants was brought up. Two solutions were proposed: 1) Make the questions less direct by asking about other factors in the person's life that would indicate such things as sexual preference or use of drugs or 2) leave the questions out of the patient schedule and put pressure on the doctor to collect that information. Both solutions were problematic. The first posed the dangers of inaccurate answers

and a perpetuation of stereotypes that would not be in the vein of good research. The second is problematic in that it depends on physician participation which had been generally difficult up to that point. After much back and forth, the team decided the best option would be neither. They opted to reorder the questions so as to disperse the more shocking inquiries with those that are more mundane, such as date of last doctor visit. They also chose to introduce most conversations about Hepatitis C through the “baby boomer angle (“Illness: From Causes to Meaning”).” This is the same angle seen in commercials for Hepatitis C. Proposing first the idea that you could have hepatitis merely because of your age shifts the blame from the patient making them feel less under “investigation.”

The issue of risk factor investigations was not only a problem for Hepis on the ground level, but was problematic for the doctors they worked with. At meetings, in general conversation, and on site visits, a recurring problem was the issue of doctor involvement in the diagnosis of HCV. What seems like the doctor’s responsibility had been neglected due to stigma and avoidance of uncomfortable situations with their patients. The Hepis found that doctors were not asking risk factor questions because they felt uncomfortable with the questions.

Risk factor awareness is an important way to decrease the number of HCV infections that occur. Transmissions often occurs when a person is unaware of their status or what behaviors caused them to become infected in the first place. These conversations need to be happening, but are often avoided for fear of stigma. The actions taken by the team to make patients more comfortable in order to gather data is having an impact larger than the grant. The continuing dialogue with these patients and providers is ultimately creating a space in which the risk factors are less stigmatized. With less stigmatization patients feel more comfortable coming forward for diagnosis and treatment. This impact is demonstrated at Prevention Point. While this is a micro

chasm in Philadelphia, the attitude of the NEP on drug use as a behavioral and health issue as opposed to criminal offense creates a safe space. Once these patients enter that judgment free zone they are more likely to be diagnosed and access treatment. The hepatitis team is contributing to a similar system wide change throughout the Philadelphia medical system.

### **Around Systems of Support**

When dealing with issue of stigma and illness, support systems are often lacking. Those who find themselves ostracized because of an illness or a behavior are less likely to reach out for help. This is evidenced by the hepatitis patient interviews where many refuse treatment or connection to a professional citing embarrassment or frustration with the medical system. The hepatitis team takes action to create a space in which support can be accessed by those who do not have other places to turn.

The main actions of the hepatitis team to support those with hepatitis come with their endorsement of HepCAP, a support group for patients who are HCV or HBV positive. This activity of providing information extends to Philadelphia clinics where they often drop materials and talk to physicians and their staff about recognizing risk factors and provide tips about encouraging compliance with transient patients. The team then takes a step further to connect these clinics and offices with the support groups and other resources throughout the city that their patients may need that the doctor is unable to provide. When interacting with patients, the hepatitis team offers materials and a direct help line that patients can feel free to call with any questions. The investigators claim that most interviews end up taking 10 minutes longer than they should because the patients end up having many questions that their doctors never addressed

with them. This one-on-one education is an important element that is unusual for public health to be able to incorporate since the focus is typically on the population rather than the individual.

These actions ultimately are constructing hepatitis in Philadelphia as something not to be feared. This is done by creating a space in which the patient feels comfortable and not discouraged by their diagnosis. They are empowered by information and are aware of the resources available to them. The team is demonstrating to doctors and communities how support can be tailored to the individual's need without much effort. They are most importantly demonstrating through support that stigma does not need to be part of the Philadelphia hepatitis conversation.

### **Around Public Health and Prevention**

The ultimate goal of public health is the prevention of disease through close monitoring, education, and quick and efficient access to treatment resources. Prioritizing prevention of hepatitis through the gathering of surveillance data is the anticipated outcome of the CDC program. By understanding the current state of hepatitis infections, the CDC can create appropriate recommendations for communities to take to halt the spread. This process involves public health, patient, physician, and community collaboration; something that the hepatitis team is working on in Philadelphia.

While interviews with already infected patients are a reactive step being taken by the team, they have many proactive initiatives as well. These actions include their collaboration with doctors on diagnostic tools, their activity at Prevention Point, and their patient education efforts. In educating doctors on diagnostic tools, they are more likely to catch cases early before the patient has the chance to infect another person. They are also able to open conversations up with

HCV negative patients about watching for behaviors that may expose them. The activities at Prevention Point stand to redefine drug use as a medical problem as opposed to one of criminal justice. Through these steps in prevention by educating on behaviors, the team is demonstrating how social and behavioral changes are part of health and prevention of hepatitis. This conversation also services to take isolated occurrences of hepatitis in the individual and contextualize them to the greater community. These actions and their results construct hepatitis to exist in a health dynamic between individuals, their communities, doctors and the PDPH which will eventually lead to lower rates of infection.

### **Around Stigmatized Behaviors and Safe Practices**

While stigmatized behaviors involving risk factors has already been touched on, this section is reserved specifically for the actions being taken at Prevention Point (PP) and through monitoring of tattoo parlors.

Through their participation in blood draws and interviews at PP, the team is able to spark a direct conversation with drug users that extends beyond the abilities of a doctor. They are meeting the users on their own turf in a space that encourages safe practices. Safe practices refers to the teaching of the use of clean needles and not sharing works, as it relates to cooking and injecting heroin. Being a part of this clinic and demonstrating to the IDUs that the PDPH does not see them as an enemy, but rather just as part of the population with health matters, it opens doors for healthy conversation. The team also actively monitors when a patient is hepatitis positive from a tattoo they receive in a Philadelphia. Close monitoring of these establishments ensures community safety and can stop outbreaks early in their tracks while encouraging best practices of needle replacement (Shaw, 2012).

The PDPH's support of NEPs and their monitoring of tattoo parlors demonstrate to community members that hepatitis is not a personal problem. It portrays hepatitis as something that the whole community can be a part of to create a healthy environment. When the team interacts with these stigmatized organizations in a supporting manner, they construct hepatitis in a safe space characterized by safe practices.

### **Around Bodily Proof and Silent Epidemics**

As previously discussed, the danger of hepatitis exists in its ability to remain in the body for decades asymptotically. This results in higher levels of damage than expected as well as a underestimation by patients of the urgency of the diagnosis. As evidenced by patient interviews, those who are diagnosed with hepatitis also feel an inclination to deny the problem is serious because they do not have bodily proof of harm. They find their friends and family do not take the diagnosis seriously because they do not exhibit jaundice or a sore liver. The hepatitis team takes direct action to give voice to the silent epidemic and establish irrelevance of bodily proof to patients.

When talking to patients about hepatitis, the investigation team resorts to a mental health analysis to make the asymptomatic yet underlying destruction clear. They avoid comparisons with HIV since there has been confusion in the past with some patients as to their diagnosis. They utilize a mental health comparison in the following way: As with a mental illness, others cannot see hepatitis or have a conception of your pain. However, in the case of both hepatitis and HIV/AIDS, the longer one goes without treatment, the worse they become until the illness is apparent to everyone. However, by that point, usually more damage is done than can ever be reversible. This analogy works well for patients in Philadelphia who often cite knowing someone

in their family with a mental illness and being able to understand the damage that invisible illness inflicted. This approach is another example of how the team caters their education to the needs and understanding of the community.

These actions demonstrate to the patients that bodily proof does not need to be a part of an illness experience. It builds awareness among those with HCV that they should not delay treatment just because the effects go unfelt for a long time. Hepatitis is therefore constructed in a space where the infected feel a sense of trust with the medical professionals and their community in understanding the urgency of their needs.

### **Around Health Insurance**

Health insurance education is not an element of the grant, but given the passage of the ACA and the necessity of insurance in receiving hepatitis treatment, the team added it to their agenda. The impacts of discussing insurance with patients may seem like due diligence, but these conversations are not happening outside of the billing offices and collection calls that patients receive. Filling this role as educator and connector is a unique role that further empowers the team and its influence in the City in the realm of hepatitis.

As previously mentioned in the background, Pennsylvania did not opt into the Medicaid expansion. This decision severely limits the state's ability to pay for the new HCV treatments that are coming onto the market. This bodes bad news for those who are on public insurance. The team directly addresses these issues through patient education, monitoring insurance statuses, and collaborating with centers of free care. By educating patients in their options for treatment and how they can access these alternatives, the team is taking steps to educate the public on health policy. The patient becomes a more active participant in their treatment. Additionally,

since their healthcare becomes politicalized through these issues of insurance, they also become more active in the political process. By politically empowering patients through education, the team is constructing a political space in which hepatitis can exist among an educated voting population seeking change in health policy.

### **Around Medical Hierarchy**

Power dynamics within medicine were brought forth through the team's interactions with both the Department of Health as well as the greater Philadelphia medical community. As previously mentioned, the investigators interact daily with physicians to conduct interviews. These interactions brought forth feelings of distrust and frustration.

The predominant way in which a medical hierarchy is observed is through the level of degree attainment. To work at the Department of Public Health, on a team such as the hepatitis program, an advanced degree is not necessary. While most people obtain masters and many have MDs or PhDs, they are not necessary to promote the ideals of public health and work in disease control and prevention. Everyone is well trained in the field that they specify in. While a doctor may need to know much more knowledge about various diseases, the hepatitis team only needs to know hepatitis, so they educate themselves to the fullest extent. This is evidenced by monthly journal clubs, attendance at hepatitis conferences, and independent research into the topic. For all intents and purposes, the hepatitis team stands as an authority on the prevention and epidemiology of hepatitis in Philadelphia, however, this authority is only as good as its recognition from the medical community, a recognition they struggle to obtain.

Compared to the patients, the doctors are given more power in how they want to respond to the surveys. Questions are first sent in the mail to the doctors to fill out at their leisure and

then fax into the Department. If there was no response from the doctors within a reasonable amount of time, the team calls and reminds them to complete the form, or opt to answer questions on the phone with them. Most opt to answer the questions on the phone, however, many others promise to fax back the completed forms ASAP. Visits to doctor's offices to perform chart audits are a weekly occurrence for the team due to lack of response.

While doctors have busy schedules, there appears to be a dynamic between the investigators and the doctors that are uncooperative in surveillance initiatives. There was a demonstrated lack of respect in the authority of knowledge of the investigation team. This was evidenced by responses given by the doctors when reminded to complete the forms that included: "This is unnecessary," "These are my patients and none of your business," and "You have no right to be asking these questions and I have no obligation to respond." These responses could be warranted reactions for the sake of protecting the patients' privacy, or as I would surmise the reason to be, the doctors' feeling that their authority and knowledge was being questioned. I come to this conclusion because after a year and a half of doctor surveys the trend was very eminent that doctors were not properly screening for hepatitis. Risk factor questions about lifestyle choices were not being asked during visits. The doctors were defensive that they were being judged for not doing their jobs properly. What the Department of Health viewed as an opportunity for collaboration and improvement of health was viewed as a turf war of authority by physicians. Fortunately, during the year and a half of field work, this dynamic began to shift as the hepatitis team demonstrated their selves to be committed and not disappearing anytime soon. Once this trust was established, collaboration on challenges grew exponentially.

Collaboration is beneficial to the PDPH and to the community. In partnership with physicians, the PDPH legitimizes itself as an authority with doctors and in the community. The

combined efforts of the two entities also mean higher effort going towards solving the problem of hepatitis. The community therefore greatly benefits from this partnership. The team is constructing hepatitis to exist in an environment in which the expertise of everyone involved in diagnosis, treatment, prevention and monitoring is respected leading to a more efficient system.

## **Conclusions**

The team gave voice to a silent epidemic by being responsible for constructing the conversations happening around hepatitis in Philadelphia. Their actions in the domains of risk factors, support systems, public health and prevention, stigmatized behaviors and safe practices, bodily proof and silent epidemics, health insurance, and medical hierarchy are contributing to determining the future climate of hepatitis in Philadelphia.

Research of this kind is not currently being conducted in the City of Philadelphia, or other urban centers in the United States. This novel investigation contributes to the HCV knowledge base in an effective and impactful way. It is my hope that this research will contribute to calling attention to the way in which the public discourse and conversations around HCV is changing in Philadelphia and how ethnographic research studies can provide insight into the behind the scenes construction of disease landscapes.

## **Limitations of the Research**

This research does not tell the whole picture of HCV in Philadelphia. It serves as a snapshot into the work of a team to assess the disease burden amidst pushback, complications, and unexpected research hurdles. In order for this research to be more complete, interviews with HCV patients are necessary. Due to IRB restrictions on vulnerable populations and a scope of a project much larger than possible for this researcher, those questions will be saved for a future project.

## **Future Research**

Understanding the disease space is important to understanding the patient experience. While this research did not approach the patient perspective, future studies must. This paper can

serve as a platform to dive off of into patient experiences. Knowing how the space for diagnosis and treatment is created can try to place the patient within a greater context. The patient experience provides necessary critiques and insights into how the clinical and research conversation created might be flawed or inefficient in its aspirations. One particular realm of interest would be research into how HCV patients in the City of Philadelphia are transformed into biological citizens by the discourse that was investigated in this research (Petryna, 2002).

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## Figure 1

Health Advisory

Enhanced Surveillance for Viral Hepatitis Beginning in Philadelphia

May 6, 2013

The Philadelphia Department of Public Health (PDPH) has launched an enhanced viral hepatitis surveillance program. The goal of this program is to better understand the burden of chronic hepatitis B and chronic hepatitis C and to estimate the level of clinical management for these diseases in Philadelphia. Surveillance information will be used to inform patient and provider educational efforts and identify additional areas for public health action.

PDPH investigators will contact providers and patients by telephone or in person to obtain clinical and risk factor information on positive hepatitis B virus (HBV) and hepatitis C virus (HCV) test reports received by PDPH. The investigations will be brief – less than 10 minutes for providers – and will provide valuable insights on Philadelphians living with chronic viral hepatitis. PDPH thanks you and your office staff for cooperating with these efforts.

We urge you to incorporate the following into your routine practice:

1. Test individuals at risk for chronic HBV and/or HCV using the following CDC guidelines:
  - Patients who test positive for HCV antibody should also be tested for HCV RNA. This distinguishes those who have an active HCV infection from those with past (inactive) infections (Please note: HCV RIBA tests are no longer recommended).
  - Patients who test positive for HBV surface antigen should have a repeat test with HBV surface antigen, HBV DNA, and/or HBV envelope antigen no sooner than 6 months after the first test. This distinguishes persons who are chronically infected with HBV from persons who have resolved acute infection.
  - All women should be screened for HBV surface antigen at the time of each pregnancy, regardless of whether they have previously had a positive or negative test result. This assists with timely provision of post-exposure prophylaxis to the infant at birth.
2. Offer Hepatitis A and B vaccination to all susceptible (HBV core antibody-negative) HCV positive patients as well as susceptible household and sexual contacts of HBV infected individuals.
3. Ask all patients about risk factors for chronic viral hepatitis, according to CDC's 'Populations at Risk':
  - Hepatitis B: <http://www.cdc.gov/hepatitis/HBV/HBVfaq.htm#b4>
  - Hepatitis C: <http://www.cdc.gov/hepatitis/HCV/HCVfaq.htm#c1>
4. Test all people born between 1945 and 1965 (ie, “baby boomers”) for HCV, regardless of risk factors.
5. Educate all patients with current HBV or HCV infection about keeping their liver healthy by avoiding alcohol and tobacco, and maintaining a healthy diet.

Please continue reporting all positive viral hepatitis test results for Philadelphia residents to PDPH within five days of receiving the results, by fax to 215-685-6947. For additional information about this project, please call the Hepatitis Epidemiology Program at 215-685-6493. To obtain resources and linkage to care information for patients with viral hepatitis in Philadelphia, please contact The Viral Hepatitis Prevention Program at 215-685-6462. Pennsylvania Code § 27 and Philadelphia Health Code § 6-202-mandate reporting of all positive HBV and HCV test results for Philadelphia residents to PDPH. These Health Codes also give PDPH the authority to investigate any reported case.

Announcement from the Philadelphia Department of Public Health to all health systems and physicians in the Philadelphia that they would be commencing increased hepatitis monitoring with the introduction of the CDC grant.

**Table 1**

<b>Action</b>	<b>Result</b>	<b>Impact</b>
<b>Realm of Influence: Risk Factors</b>		
<ul style="list-style-type: none"> <li>-Downplays their stigma through emphasis of “baby boomer” angle in interviews</li> <li>-Educate doctors about risk factors and how they can facilitate healthier conversation with their patients about them</li> </ul>	<ul style="list-style-type: none"> <li>-Garners higher response rates on surveys about risk factors</li> <li>-Creates more detailed patients records with their primary physicians</li> <li>-Creates a healthier repertoire between doctor and patient</li> </ul>	<p>An elimination of stigma from the conversations around diagnosis of hepatitis empowering patients to be tested without fear of judgement.</p>
<b>Realm of Influence: Systems of Support</b>		
<ul style="list-style-type: none"> <li>-Present at support group meetings</li> <li>-Connect support groups to each other</li> <li>-Created information cards and appointment cards for patients at Prevention Point</li> <li>-Translate letters and phone calls for non-English speaking patients</li> </ul>	<ul style="list-style-type: none"> <li>-Creates a network of HCV awareness</li> <li>-Help eliminate stigma</li> <li>-Creates a space in which patients and providers can feel more comfortable with diagnosis and treatment</li> <li>-Demonstrating how support needs to be tailored to an individual’s needs</li> </ul>	<p>A space in which patients feel comfortable and not discouraged with their diagnosis because they are aware of the resources available to them.</p>
<b>Realm of Influence: Public Health and Prevention</b>		
<ul style="list-style-type: none"> <li>-Educate patients and community leaders on the interconnectedness of diagnosis and prevention</li> <li>-Volunteer at Prevention Point</li> <li>-Distribute materials to patients and doctor’s offices</li> </ul>	<ul style="list-style-type: none"> <li>-Demonstrating how social and behavioral changes are a part of health</li> <li>-Takes isolated occurrences of HCV and contextualizes them in a way that makes HCV a community concern-</li> </ul>	<p>A healthy dynamic between individuals, their communities, doctors and the Department of Public Health that leads to efficiency and lower rates of infection.</p>
<b>Realm of Influence: Stigmatized Behaviors and Safe Practices</b>		
<ul style="list-style-type: none"> <li>-Volunteer at Prevention Point</li> <li>-Educate doctors on these risk factors that are associated with stigmatized behaviors</li> <li>-Educate intravenous drug users on safe practices</li> <li>-Encourage condom use</li> <li>-Monitor tattoo parlors and reports of infection</li> </ul>	<ul style="list-style-type: none"> <li>-Transforms these behaviors and choices from social problems to issues of public health</li> <li>-Create a safe space for discussion of these behaviors without judgment</li> <li>-Create a safe community in which behaviors do not have to result in infection</li> </ul>	<p>Decreased stigma among the community regarding drug use that leads to healthier communities and safe practices.</p>
<b>Realm of Influence: Bodily Proof and Silent Epidemics</b>		
<ul style="list-style-type: none"> <li>-Educate on being asymptomatic</li> <li>-Educate using analogies to mental</li> </ul>	<ul style="list-style-type: none"> <li>-Demonstrate that bodily proof is not the only part of illness</li> </ul>	<p>Creates trust between the infected and their community as to the</p>

health -Educate on the frequency of HCV	-Build awareness among those with HCV that they shouldn't await diagnosis and treatment -Allows patients to know they are not the only ones with HCV	urgency of their needs.
<b>Realm of Influence: Health Insurance</b>		
-Educate patients in insurance options -Volunteer at Prevention Point	-Raises awareness of flaws -Creates an active participant in one's medical treatment -Creates a space for protest against the system -Empowers patients	Creates an educated voting populace who can demand change in health policy.
<b>Realm of Influence: Medical Hierarchy</b>		
-Work with doctors on data collection -Perform chart audits when doctors do not comply	-Enforces the authority of the Department of Health with doctors -Creates collaboration with doctors encouraging teamwork on difficult cases	Creates an environment in which the expertise of everyone involved in diagnosis, treatment, prevention and monitoring is respected.

Table outlining the actions that the hepatitis team takes during implementation of the CDC grant with observed results of the actions and surmised broader impacts of these actions.