Examining Hepatitis C Treatment in Chicago: Current Barriers and Future Opportunities for Change

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Abstract

Hepatitis C is the deadliest infectious disease in the United States[1]. While there is treatment available for hepatitis C, Medicaid guidelines in many states throughout the United States place severe restrictions on who can access treatment, including Illinois. In Illinois, there are liver fibrosis restrictions, sobriety restrictions, and prescriber restrictions that all make it difficult for patients diagnosed with hepatitis C to receive care. Brief exploration of the data for patients who have a hepatitis C diagnosis in Chicago community health centers has shown that many patients who are diagnosed with hepatitis C do not follow-up with treatment, which could be due to these statewide restrictions. However, this must be explored further to determine what barriers to care individuals diagnosed with hepatitis C are facing. In this analysis, methods included chart auditing and quantitative and qualitative extractions from patient electronic health records. Results from this study found that 1) patients with Medicaid and fibrosis Stages 0 - 2 were unable to access treatment, 2) inadequate referral processes led to inefficient care cascades and gaps in patient data, and 3) date of birth, as well as a history of intravenous drug use, remain large risk factors for hepatitis C infection. The results from this study can inform improved care cascade guidelines for providers to use to best care for patients diagnosed with hepatitis C as well as guide advocacy efforts to alleviate the restrictions that Medicaid has on treatment for those diagnosed with hepatitis C.

Background

The State of Hepatitis C

Hepatitis C is a contagious liver disease that is caused by an infection with the hepatitis C virus. It is usually spread through contact with the blood of someone infected with hepatitis C such as through needle sharing or blood transfusion from someone infected with hepatitis C. There are current treatment methods available that can cure the infection. Acute hepatitis C is a short-term illness and occurs within the first six months of infection with the hepatitis C virus. If the infection goes untreated, it advances to chronic hepatitis C, which is a long-term illness that can lead to severe liver scarring and/or liver cancer[2].

The CDC estimates that as of 2014, there were 30,500 reported cases of acute hepatitis C virus infections, and 2.7-3.9 million reported cases of chronic hepatitis C infections in the United States. Groups of people that are disproportionately affected by hepatitis C infection include baby boomers (born between 1945 and 1965), inmates, veterans, and non-Hispanic black men[3]. Baby boomers are five times more likely to be diagnosed with hepatitis C as compared to other adults, which is a result of the way that hepatitis C is spread. Lack of universal procedures to keep medical equipment and facilities sanitized prior to adoption of current laws could have led to the increased spread of the virus to the population born between 1945 and 1965. Also, prior to 1992, there was no hepatitis C virus screening protocol in place for blood that was collected for donation or transfusion. These two mechanisms are the primary hypotheses for an increased prevalence of hepatitis C in baby boomers as compared to other adults[4]. Last, it is estimated that 75-85% of people who become infected with hepatitis C develop chronic hepatitis C infections because their acute infection goes untreated[2]. Therefore, there is a major gap in treatment of

hepatitis C that must be filled to prevent individuals' infections from advancing from acute infection status to chronic infection status.

Ideal Care Cascade

The American Association for the Study of Liver Diseases, in conjunction with the Infectious Diseases Society of America, published guidelines in September of 2017 regarding best practices for testing, treating, and managing hepatitis C in the United States. First, they discuss who should be tested for hepatitis C and how frequently they should be tested. They state that anyone born between 1945 and 1965 should be tested once, regardless of the presence of additional risk factors. Also, anyone with any history of risk behaviors or risk exposures such as injection drug use or individuals with a history of incarceration should be tested at least once. If the risk behaviors are continuous, individuals should be tested on an annual basis, or on another schedule that the provider deems fit. Each of these initial tests should be a hepatitis C virus antibody test, to be followed up with additional testing if the antibody test comes back positive. Following a positive antibody test, a hepatitis C RNA test should be conducted to confirm current infection with hepatitis C. After confirmation of a current hepatitis C infection, the genotype of the virus should be measured to ascertain which medication will be best to clear the infection. The last step in the testing phase is to get imaging done of the liver in order to get a handle on the fibrosis level of the patient.

Then, while awaiting treatment for hepatitis C, patients should be advised to do several things to manage the illness. Patients should be educated about how to prevent transmission of hepatitis C to others, and should also be educated about the hepatitis C virus to prevent future reinfection. Also, patients should be evaluated for other infections such as hepatitis B virus and HIV, because the presence of these two infections can exacerbate the damage done by hepatitis

C. Last, patients should attend all follow-up visits and referrals for treatment or testing to ensure that treatment is done in a timely manner.

Last, treatment must be initiated for the patient. With today's advances in hepatitis C treatment technology, hepatitis C can be cured with medications. The point at which someone diagnosed with hepatitis C is cured is referred to as sustained virologic response (SVR). Recommendations put forth by these two organizations states that treatment is recommended for all patients with chronic hepatitis C infection, other than those who have a shortened life expectancy that will not benefit from hepatitis C virus therapy. Studies have found an increased benefit for beginning treatment for the hepatitis C virus in Stages 0 and 1 of liver fibrosis. Patients who achieved SVR after only reaching fibrosis Stages 0 or 1 had a 93% survival rate fifteen years later as compared to a survival rate of 83% for individuals who did not complete treatment and a survival rate of 88% for individuals who did not begin treatment at this time. Also, it was found that patients who did not gain access to treatment until Stages 3 and 4 of liver fibrosis had a two and five times higher rate of liver related mortality, as compared to patients who were treated at Stage 2 of liver fibrosis. The above data supports the need to begin treatment as soon as one is diagnosed with hepatitis C[5].

Evaluation of Hepatitis C Treatment Access in the United States

In 2017, the National Viral Hepatitis Roundtable worked with individuals from the Harvard Law School Center for Health Law and Policy Innovation to evaluate the state of Medicaid access for hepatitis C treatment, by state. A letter grade was given to each state based off of several metrics that measured how accessible treatment for hepatitis C is. In Illinois, it is estimated that 68,400 people are living with Hepatitis C. In terms of Medicaid access to treatment, Illinois received a D- grade because of several factors. First, all fee-for-service,

primary care case management, and most Managed Care Organization insurers require that patients reach Stage 3 of liver fibrosis, which is characterized by severe liver damage. This is an improvement from laws previously in place in Illinois that required that patients reach the final stage of Stage 4 of liver fibrosis. However, policies for treatment coverage must be improved to allow for care to occur before patients incur severe liver damage.

Next, all Medicaid insurers in Illinois have some level of sobriety restrictions for those seeking care for hepatitis C. The restrictions vary but include rules such as a screening for active substance use, six months sobriety, or participation in an alcohol or substance use treatment program. Last, Illinois Medicaid insurers require that a specialist write a prescription for hepatitis C treatment coverage. This is limiting for many reasons, including patients' access to specialist care due to insurance status, income, or distance to the nearest specialist and primary care providers' challenges in referring patients to specialists when they have the training and ability to care for the patient in the primary care setting. In addition, wait times to see a specialist for many under- and uninsured is significant, with some waiting months to see a hepatologist. Overall, the severe restrictions placed on access to hepatitis C treatment for Illinois Medicaid recipients makes it difficult for the most vulnerable populations to receive care[6].

Oppositely, Connecticut was the only state to receive an A+ rating by this Medicaid access analysis. It is the first state to provide access to hepatitis C treatment for all beneficiaries over age 12 with no restrictions relating to liver fibrosis stage, sobriety, or prescriber. Other states including Illinois must follow suit behind Connecticut to provide more holistic care for patients suffering from hepatitis C[7].

AllianceChicago and Previous Work

AllianceChicago, a national Health Center Controlled Network (HCCN), is focused on improving personal, community, and public health through innovative collaboration. Founded in 1997 by four community health centers located in Chicago (Heartland Health Outreach, Erie Family Health Center, Howard Brown Health Center, and Near North Health Service Corporation), today, AllianceChicago represents an additional 28 community health centers in 19 different states. Their work is divided into three main areas: healthcare collaboration, health information technology, and health research and education. At the crux of their organization is the importance of the community health centers they work with, and therefore the communities that they serve. They work on a variety of projects in the Chicagoland area as well as nationally in an effort to improve health of individuals and communities[8].

The project under focus in this analysis falls within the health research and education department at AllianceChicago. The goal of this division is to conduct research and educational activities that are designed to benefit the patients, providers, and broader communities. In order to conduct their research, AllianceChicago has a technological infrastructure that virtually connects the electronic health record data from all network community health center sites with AllianceChicago's database under one electronic health record system. This allows easy access to necessary data to improve the health of communities throughout those communities represented as a part of the network[9].

AllianceChicago is currently collaborating on the Hepatitis C Community Alliance to Test and Treat (HepCCATT) project. This project was conducted in conjunction with the University of Chicago, AllianceChicago, community and academic organizations in Chicago, and Chicagoland community members. The main goal of HepCCATT is to reduce the number of undiagnosed and untreated individuals suffering from hepatitis C infection in Chicago.

HepCCATT is addressing this problem by raising public awareness about hepatitis C among target groups, training healthcare providers to test and care for hepatitis C at community health centers, sharing knowledge about changes in clinical diagnosis of hepatitis C, and expanding access to hepatitis C care through advocacy and engagement with different community members[10].

As a part of the HepCCATT project, staff at AllianceChicago observed that data reported that the majority of patients were not being treated for Hepatitis C after being diagnosed, which they knew was untrue. They noted that the data that was being pulled from structured electronic health record fields did not tell the whole story when it came to treating hepatitis C. For example, when they pulled data on patients eligible for treatment who did not show that they were treated, they recognized that there was a legitimate reason why treatment did not occur. For example, some patients had comorbidities such as cancer and were too sick for hepatitis C treatment. Additionally, for some patients, Medicaid denied their requests because of past or current substance use. These observations led to the current project under analysis, which is set to examine trends in why patients who were eligible for hepatitis C treatment did not ultimately receive treatment.

Public Health Relevance

This project aligns with the Community Health Research concentration in the Master's of Public Health program at Northwestern University because of its focus on positively impacting the health of the community. Not only this, but also AllianceChicago recognizes the importance of engaging community members in research efforts, and is working alongside staff at partnering community health centers to guide the research plan. Working on this project will help to further develop the skills I have gained in courses focused on community health research by allowing

me to apply subject matter to the field. Additionally, results from this study can greatly impact the field of public health. Just as there is a defined care cascade for HIV, this work can help to develop an improved care cascade for patients diagnosed with hepatitis C. Last, results from this study can support advocacy efforts in Illinois and other states with strict restrictions on hepatitis C treatment for Medicaid recipients to hopefully eliminate restrictions and allow treatment for all who are diagnosed.

Research Question

The main research question in this study is to determine why data for patients who are diagnosed with hepatitis C state that they are not receiving treatment. It is hypothesized that for patients who do not receive treatment for hepatitis C, it will be because of restrictions placed on them by insurance or because of presence of a comorbidity that reduces their ability to go through treatment. Past opinion on this topic is that patients who are diagnosed with hepatitis C but do not receive treatment are either lost-to-follow-up or are lost down the cracks in the healthcare system, but it is the aim of this study to uncover exactly why treatment is not reported in some cases.

Methods

A mixed methods study design was used, with chart auditing, qualitative note extraction, and quantitative electronic health record data being the main methods for data analysis. The Chicago Department of Public Health IRB approved this study for exemption before beginning the research process. AllianceChicago staff contacted all partnering community health centers throughout Chicago to gain consent to access patient data for the purposes of this project. After approvals were collected from the community health centers, patient charts were pulled by AllianceChicago data architects. Eligibility criteria included patients who had: either positive

RNA laboratory test, or hepatitis C diagnosis with start and end date listed and a positive RNA laboratory test, or hepatitis C diagnosis only with accompanying information in the chart from provider with further detail. The total sample was comprised of 813 patients across seven community health centers throughout Chicago. A stratified random sampling was used in which a 10% sample was drawn from the seven community health centers, with each community health center's contribution proportional to their total number of patients with a confirmed positive hepatitis C status. All chart information was collected and reported using de-identified patient ID numbers to retain patient privacy.

A total of 81 patient charts were audited for 35 factors. First, demographic questions were recorded. This included sexual orientation, gender identity, housing status, insurance status, employment status, poverty level, zip code, education level, race/ethnicity, age, score on a PHQ-9 test measuring level of depression, veteran status, and substance use. Next, additional comorbidities were recorded such as intravenous drug use and HIV status because of their interconnectedness with hepatitis C treatment and care. Then, hepatitis C specific data was collected. This included the stage of liver fibrosis, RNA screening for hepatitis C, antibody screening for hepatitis C, hepatitis C genotype, and other information written in document notes by the provider pertinent to the hepatitis C diagnosis. Last, the reasons for lack of treatment were quantified for analysis or the status of treatment was reported. Reason for lack of treatment was categorized as Medicaid ineligible due to a low liver fibrosis score, current substance use, referral to outside specialist, or too sick for treatment based on presence of other comorbidities.

In addition to this quantitative data, qualitative data was extracted from the patient charts to provide increased understanding of the data that was drawn from the chart audits. This data was collected from providers' free text notes documented in the patient charts and not available

in a standardized/formal data field. This qualitative data was extracted and quantified for an additional analysis piece to improve quality of the quantitative data that was collected in the auditing step.

Following the chart auditing procedure, the data collected was analyzed using a frequency analysis in *Microsoft Excel 2013*. A demographic descriptive analysis was first completed to show the distribution of patients who will be included in the analysis. Then, figures were produced in *Microsoft Excel 2013* to show the distribution of patients who fall into several categories. These categories include the following: number of patients who are treated by fibrosis score, number of patients who are lost in the referral loop, number of patients who have a positive RNA test based on risk factor, and classification of treatment status for RNA positive patients.

Last, the findings were presented to the providers at the community health centers involved in the study. There will be ongoing collaboration on the topic to continue to work toward improving patients diagnosed with hepatitis C in Chicago.

Results

Several analyses were completed to synthesize the data. First, the demographics of the group were assessed. As can be seen in Table 1, 62% of the sample identified as males, 36% identified as females, and 2.5% identified as transgender individuals. Also, the majority of the sample was found to live in a steady home, is unemployed, and also is insured by Medicaid. Additionally, the two races most represented were White and Black, and most patients in the sample were not Hispanic or Latino. The largest age group in the sample was between 56 and 65 years of age, and most individuals used a combination of drugs and alcohol. Last, most of the

sample does not have veteran status. These demographic factors can be reflected upon during analysis to put the data into perspective.

Next, Figure 1 displays the number of individuals who had a positive RNA lab result separated by risk factors to understand which risk factors were most prominent. It was found that in this sample of individuals, date of birth between 1945 and 1965 was the most predominant risk factor in the group of individuals who had a positive RNA lab result, with 47% of the sample having date of birth as a risk factor. The second largest group of individuals with a risk factor for hepatitis C diagnosis was those who had a history of using intravenous drugs, with 33% of the RNA positive group having intravenous drug use as a risk factor. Last, it was seen through this analysis that there were few individuals who had none of these risk factors present, with only 20% of those who were diagnosed having no risk factors. These finding were expected, as hepatitis C is found most frequently in these two at-risk groups[5].

Also, results were quantified based on fibrosis score and treatment statuses of individuals who were diagnosed with hepatitis C. Of the total 81 patients in the sample, 27 patients had their fibrosis score listed, as well as their treatment status, in their medical charts. This data is portrayed in Figure 2. The majority of patients with a liver fibrosis score listed in addition to their treatment status had Stage 0 of liver fibrosis, which indicates minimal to no liver damage. Of this group of individuals who had Stage 0 of liver fibrosis and treatment status listed, 70% of patients were not treated. Further, of the patients who were treated with a fibrosis Stage of 0, two-thirds of the patients were on private insurance, which places no restrictions on treatment at this early stage of liver fibrosis. On the opposite end of the spectrum, for patients listed with Stage 4 of liver fibrosis in conjunction with a treatment listed in his or her medical chart, about 67% of patients were treated. These results were expected because of the laws in place in Illinois

that prohibit patients on Medicaid from receiving treatment until they are in Stage 4 of liver fibrosis. This sample was drawn from a population as new laws were being passed in Illinois changing the restrictions from Stage 4 of liver fibrosis to Stage 3 of liver fibrosis, and therefore individual treatment could be based upon the old or new laws.

Additional qualitative data was extracted from patients' electronic health records to provide a better understanding of the quantitative data listed in the charts regarding fibrosis score and treatment. For example, for patients who were found to have a liver fibrosis Stage of 0 - 2, it was common to see providers request that patients return every six months to monitor progression of disease and specifically, liver fibrosis status. For patients who did not have a fibrosis stage listed at all in the chart, providers usually had a note in the chart to send the patient for a FibroSure scan or to refer to a hepatologist to have follow-up testing done. Last, for patients who had a fibrosis Stage of 3 - 4 written in the chart, it was common that providers wrote to apply for treatment through insurance because their fibrosis score had reached a high enough level to be approved through insurance. This illuminates the average care cascade that is seen in Chicago for Medicaid patients who have varying fibrosis levels.

Next, an analysis was conducted to examine how referrals affected treatment status. Another law in Illinois states that in order to receive treatment, a hepatologist must write the prescription for care. Therefore, the primary care providers who provide care at the community health centers throughout Chicago are unable to prescribe treatment without coordination with a hepatologist at an outside clinic. Also, as was described earlier, in order to be eligible for treatment under Medicaid in Illinois, the patient's liver fibrosis stage has to be at least at Stage 3. In order to measure fibrosis stage, a patient must be referred to an outside clinic that has the capacity to take liver ultrasounds and FibroSure scans. Therefore, there is a step in which

patients must be referred out at diagnosis and at treatment, because the community health centers in this sample do not have the capacity to do either at the current time. This both places the responsibility on the patient and halts efforts to keep a patient's care at their patient centered medical home.

Through provider notes it was identified that patients often have difficulty fulfilling these referrals and an analysis was completed to understand how many patients are lost to care because of an inability to close the referral loop either at diagnosis or treatment. As can be seen in Figure 3, it was found that 15% of patients with a positive RNA result in the sample were referred to a hepatologist for treatment but neither the patient nor specialty clinic followed-up with the primary care provider at the community health center with current hepatitis C treatment status. Next, it was found that 29% of patients with a positive RNA result in the sample were referred out to complete imaging or other testing for hepatitis C diagnosis, but never returned to the community health center to follow-up on a treatment plan. Closing the referral loop is an important factor in any sort of treatment plan, because care can no longer be coordinated for a patient who has an unknown status after a referral. A further analysis can posit the reasons why this may have occurred, including lack of a state health information exchange and/or bi-directional interoperability between electronic health record systems, but expanding the data to include more individuals would have to be completed to gain a more accurate explanation for this discrepancy.

In addition to this data, there were many provider notes in the patient charts that focused on how the referral process affected patients diagnosed with hepatitis C. Providers noted in the electronic medical records when they referred patients for care outside of their primary care community health center, such as hepatologists, as well as if they referred patients for additional

tests related to their hepatitis C in order to keep track of their patients' care. These tests included blood tests to test for RNA positivity of hepatitis C, liver ultrasounds to check the status of the liver, FibroSure scans to monitor fibrosis stage, and antibody tests to check for exposure to the hepatitis C virus. In addition to noting where they were sending their patients, providers also noted the number of times that they referred their patients for specific services. A general trend was found in these qualitative notes from providers that 50% of the time that patients were referred for tests, the referral would have to be repeated several times because of miscommunications between providers or a lack of compliance per the patients. Also, there was data found that while patients may attend their referral visits, it is common for it to take several requests for the results to be sent back to the provider who gave the referral. As was also seen in the quantitative results presented previously in Figure 3, it is common for providers at these community health centers to never receive information back from referrals to know if their patients were able to receive treatment or not.

Additionally, an analysis was completed to quantify the total number of individuals who were able to complete treatment after having a hepatitis C diagnosis based on a positive RNA lab test. As shown in Figure 4, 55 total patients in the sample had a positive RNA test for the hepatitis C virus. Of this total, 27% were treated, 15% were not treated, and 58% had an unknown treatment status. This data was drawn from a combination of qualitative and quantitative data, because providers usually only indicated a treatment status in a free text note rather than the standardized electronic health record flowsheet where the rest of the hepatitis C data was listed. For those who were treated, providers were able to indicate a date on which the viral load was cleared. For those who were not treated, there was a distinct reason in the chart such as a lack of approval by insurance because of a low fibrosis score or comorbidity such as

HIV, which reduced the patient's ability to begin treatment. For these patients, there were also notes that indicating the need for the patients to continue to follow-up periodically to monitor the infection and move toward treatment in the future. For the last group of individuals who did not have a known treatment status, the largest reason why was because of the previously discussed issue with closing the referral loop. Provider notes indicating a need to get access to information from referral visits or needing the patient to follow-up after a visit with a specialist were the most common, preventing them from knowing a patient's treatment status.

Overall, these data show the difficulties that patients face in accessing treatment for hepatitis C and illuminates the need to improve the care cascade for those living with hepatitis C as well as improve advocacy efforts to reduce the treatment restrictions on patients with Medicaid insurance.

Discussion

Analysis and Recommendations

The main research question in this study was to determine why patients who are diagnosed with hepatitis C do not receive treatment. It was hypothesized that for patients who did not receive treatment for hepatitis C, it would be found that this was because of restrictions placed on them by insurance or because of presence of a comorbidity that reduces their ability to go through treatment. Prior to this research study, opinion on this topic was that patients who were diagnosed with hepatitis C but did not receive treatment were either lost-to-follow-up or were lost down the cracks in the healthcare system. Therefore, it was the aim of this study to uncover exactly why patients in Chicago who are diagnosed with hepatitis C are not treated in order to bridge gaps in knowledge on the topic and introduce policy changes.

Through chart audits and further analysis, the main research question was explored. While there was limited data present in patient charts regarding the effect that comorbidities played on hepatitis C treatment, there was a large body of data supporting the alternate explanation that patients are restricted to treatment due to Medicaid insurance requirements. The insurance requirement that was found to be most restricting to patients was that of the fibrosis stage required to qualify for insurance coverage under Medicaid.

First, it was shown that various patients who had liver fibrosis stages less than 3 did not receive treatment. Accompanying qualitative data from the providers' descriptions in patient charts supported the hypothesis that the reason patients were left untreated was due to a low liver fibrosis stage. Rather than being able to begin treatment for these patients, providers must keep notes for patients with low liver fibrosis stages to ensure that they follow-up frequently in order to track the progress of their fibrosis until they reach a high enough level of liver damage to qualify for treatment. This was not true of patients who were on private insurance, as Figure 1 shows. For patients who had both fibrosis stage and treatment status listed, two out of the three patients who were treated at a fibrosis stage lower than 3 were under private insurance. This law that restricts patients under Medicaid coverage in Illinois from gaining access to treatment until their liver damage reaches an advanced stage is discriminatory because it prevents those who cannot afford to pay for private insurance from being as healthy as those who can afford to pay for private insurance.

In December 2016, a systematic review was conducted to expand understanding about the importance of early detection and treatment of hepatitis C to improve the long-term health of patients diagnosed with hepatitis C. The review looks specifically at the effect of achieving SVR on long-term health and economic outcomes. Overall, 354 studies were identified that met the

criteria put in place for the systematic review. Inclusion criteria included retrospective or prospective studies reporting mortality, liver morbidity, extrahepatic manifestations, and economic outcomes for patients living with chronic hepatitis C. Of the 354 total studies found, data from 38 studies including 73,861 patients showed a significant mortality benefit in achieving SVR for patients in all stages of liver fibrosis, rather than just the higher stages of liver fibrosis. Additionally, studies that included a follow-up period of five to twelve years showed that especially for patients without liver cirrhosis at time of treatment, SVR decreased mortality as compared to patients who did not reach SVR. Also, 99 studies including a total of 235,891 patients showed that SVR in patients of all stages of liver fibrosis significantly decreased liver-related mortality and incidence of hepatocellular carcinomas. Last, four of the studies included in the systematic review created models that showed that delaying treatment for individuals diagnosed with chronic hepatitis C based on early liver fibrosis stage leads to significant increases in mortality, morbidity, and clinical costs[11]. In general, this study provides an impetus to advocate for a change in the Medicaid requirements in Illinois and other states restricting treatment for hepatitis C treatment until later stages of liver fibrosis because there are long-term benefits in terms of cost and patient health for beginning treatment at earlier stages of liver fibrosis.

Next, the data shows the importance of improving the referral structure in community health centers in Chicago. As was discussed in the results section, there are two points in the hepatitis C care cascade that patients must be referred out for care: at diagnosis and at treatment. First, for full diagnosis of hepatitis C, a FibroSure scan must be completed to assess the level of liver fibrosis. Ultrasounds are also often suggested in order to assess the health of the liver. Community health centers in Chicago do not have the capacity to complete these tests in-house,

which makes it necessary for patients to travel to additional doctor's visits to get the tests completed. Most patients in this sample are on Medicaid and are unemployed, which makes it highly likely that they face additional barriers to accessing care due to their socioeconomic status. For example, access to transportation is a common barrier for patients with a low socioeconomic status. Without adequate access to transportation, it is more difficult for patients to attend doctor's appointments, especially if these visits are more frequent with the need to attend multiple visits for referrals[12]. Additional barriers that individuals in low income families face include an inability to take off from work to make it to doctor's appointments and issues finding childcare coverage so that they can leave their home for appointments. Streamlining the care cascade to allow for these tests to be completed at the community health center could improve compliance with care, because it would reduce the need for patients to attend multiple visits. However, this is a costly and difficult solution because it would require that community health centers gain access to the technology and staff to conduct these tests in their healthcare centers. Additional solutions must be developed in order to improve how patients can gain better access to these resources.

Additionally, the data presented displays the need for an improvement in the documentation of referral visits, or "closing the referral loop," in the electronic health record system. Figure 4 shows that over half of those who were diagnosed with hepatitis C in this sample have an unknown treatment status because of a lack of specification in patient charts regarding their status. It is important that the entire course of the patient's diagnosis, management, and treatment is described in the patient chart in order to properly coordinate future care. Figure 3 also illuminates this issue in portraying the number of patients who are lost to in the referral loop either at diagnosis or treatment. Physicians cannot properly follow-up with

patients if notes from referral visits are not added to the patient charts. Not only is closing the referral loop an issue in Chicago, but it is a nationwide issue that must be addressed. Patel and colleagues conducted a study in 2018 that examined problems associated with closing the referral loop in a large healthcare system. They found that only 34.8% of a total of 103,737 referrals accurately closed the referral loop, which includes complete documentation from the appointment that is readily available to the patient's primary care provider[13]. Improving providers' abilities to close the referral loop in the electronic medical records system is another large action item for the system to undertake because it would require an overhaul of the electronic medical records system to improve how patient referrals are documented. However, it is an important change that could positively affect how patients living with hepatitis C in Chicago are cared for, and collaborative efforts will be undertaken with Chicago community health centers to improve this issue.

Last, the majority of patients infected with hepatitis C in this sample have either date of birth or intravenous drug use listed as risk factors for developing hepatitis C. These are the two most common risk factors for contracting hepatitis C in the United States, and they must be addressed in order to reduce the rate of infection and improve the health of individuals already infected. Date of birth cannot be prevented, but rather structures can be improved to increase the number of patients who are screened and treated for hepatitis C to reduce the number of patients who wait until end stages of liver failure to seek out treatment. For example, TPAN, an AllianceChicago network member and organization located on the North Side of Chicago, provides confidential and free HIV and hepatitis C testing in an office and mobile unit. Increasing knowledge around resources such as this can increase the number of individuals at risk who are tested, which can improve health outcomes[14]. Also, conducting educational

outreaches to educate individuals born between 1945-1965 or intravenous drug users about their risk of having hepatitis C can increase the rate of those who seek out testing for the virus. Although it is suggested that all individuals born between 1945 and 1965 get tested, it has been cited that only about half of these individuals have been tested[4]. Therefore, local educational campaigns, such that is also being done by HepCCATT, must be expanded in order to improve knowledge about the importance of testing for hepatitis C. Last, educating those who use intravenous drugs about the risks associated during counseling sessions or primary care provider visits could potentially reduce the number of individuals who are infected in this manner.

Limitations

This analysis has several limitations that must be discussed. First, this only represents a small sample of the patients living with hepatitis C in the Chicago, which is only representative of a small sample of the population living with hepatitis C in the United States, overall. Therefore, the results cannot be generalized further than patients who seek care at the seven community health centers represented. However, it is a small step toward uncovering the issues that patients living with hepatitis C have in the larger context. Additionally, there are many gaps in the data that prevent the entire sample to be used for analysis because not all patients had the auditing factors listed in their patient charts. Expanding the sample to a larger group could improve future data and analysis. Next, there was only one individual auditing the charts, which could have led to a slight bias in findings. Confirming findings across different auditors could improve the reliability of the data. Last, this data represents only what was written in patients charts from the community health centers. Having conversations with patients and providers who have lived experiences with hepatitis C could improve the quality of the data collected and create a more robust analysis.

Conclusion

Hepatitis C is the deadliest infectious disease in the United States. Although there is a very effective treatment method available, there are still gaps present in those who are able to access care. Through an analysis of chart audit data and provider notes in patient charts, this project has been able to illuminate some of the issues that patients living with hepatitis C in Chicago face. First, because Medicaid places a restriction on who can access care based on the level of liver fibrosis that a person has, only those with Stages 3 and 4 of liver fibrosis are able to get treated. This prevents individuals who are recently infected from getting care, which has long-term effects on their health. Advocacy efforts must focus on this issue in order to eliminate further restrictions by Illinois state law. Also, insufficient documentation and a problem with closing the referral loop prevents patients from having coordinated care for their hepatitis C. Primary care providers at these community health centers voice frustration when attempting to get documentation from patients' visits with other providers, because the information from those visits are necessary in order provide high quality hepatitis C care. Improving the referral process and coordination of care with primary care providers could thereby improve the way that patients in Chicago are able to receive care for hepatitis C.

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Appendix A

Demographics			
	Total	81	100.0%
Gender Identity	Male	50	61.7%
	Female	29	35.8%
	Trans	2	2.5%
Sexual Orientation	Straight	22	27.2%
	Gay	2	2.5%
	Lesbian	0	0.0%
	Not Listed	57	70.4%
Housing Status	Steady Home	65	80.2%
	Homeless	16	19.8%
Insurance Status	Medicaid	50	61.7%
	Medicare	11	13.6%
	Sliding Scale Fee	15	18.5%
	Private	5	6.2%
Employment Status	Employed	13	16.0%
	Self-Employed	1	1.2%
	Student	2	2.5%
	Unemployed	57	70.4%
	Not Listed	8	9.9%
Primary Race	White	32	39.5%
	Black	46	56.8%
	Asian	2	2.5%
	American Indian/Alaska Native	0	0.0%
	Native Hawaiian/ Pacific Islander	0	0.0%
Ethnicity	Hispanic or Latino	12	14.8%
	Not Hispanic or Latino	69	85.2%
Age	25 or Younger	3	3.7%
	26-35	14	17.3%
	36-45	9	11.1%
	46-55	13	16.0%
	56-65	32	39.5%
	66-75	9	11.1%
Substance Use	Yes- Alcohol	7	8.6%
	Yes- IVD	8	9.9%
	Yes- Combination	42	51.9%
	Yes- Other Drugs	5	6.2%
	No	15	18.5%
Veteran Status	Yes	3	3.7%
	No	78	96.3%

Table 1. Demographics for the total sample, n=81.

*1 patient excluded for lack of data

**1 patient is deceased, so data point is excluded from age category

**4 patients excluded for lack of data

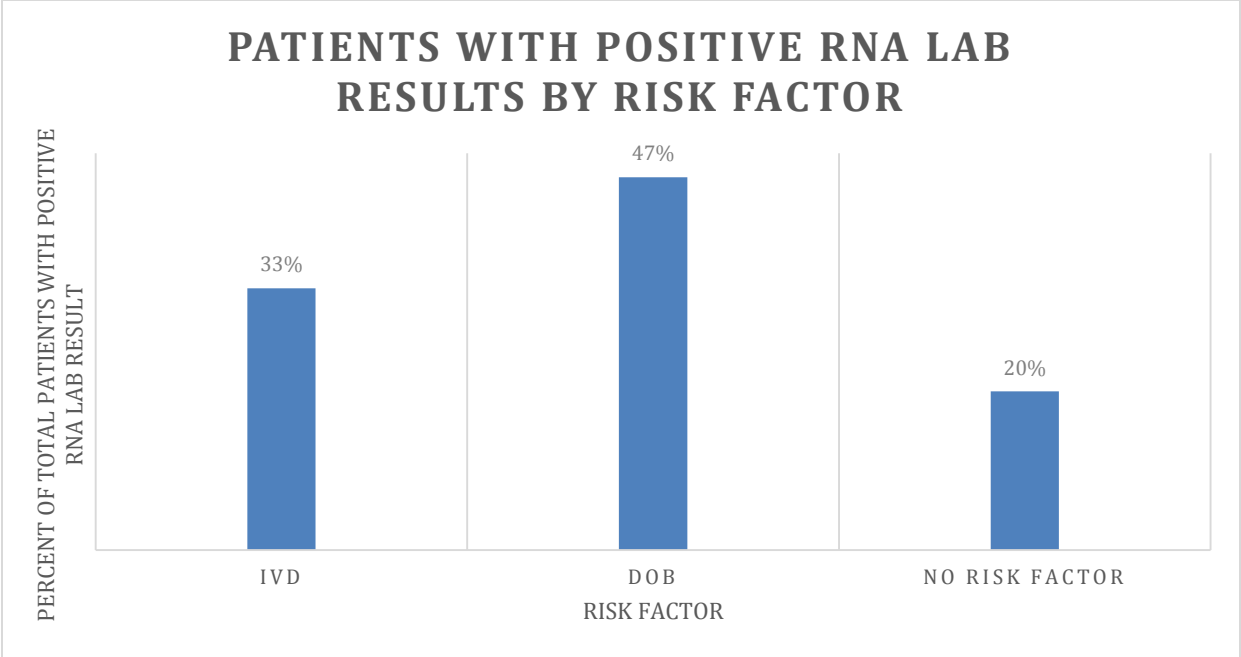

Figure 1. Percent of patients with a positive RNA lab test result with the following three different risk factors: History of IVD use, Date of Birth between 1945-1965, No Risk Factors Mentioned. The highest percentage of people was found to have the date of birth risk factor, and the lowest percentage of people had no risk factor present. (n=55)

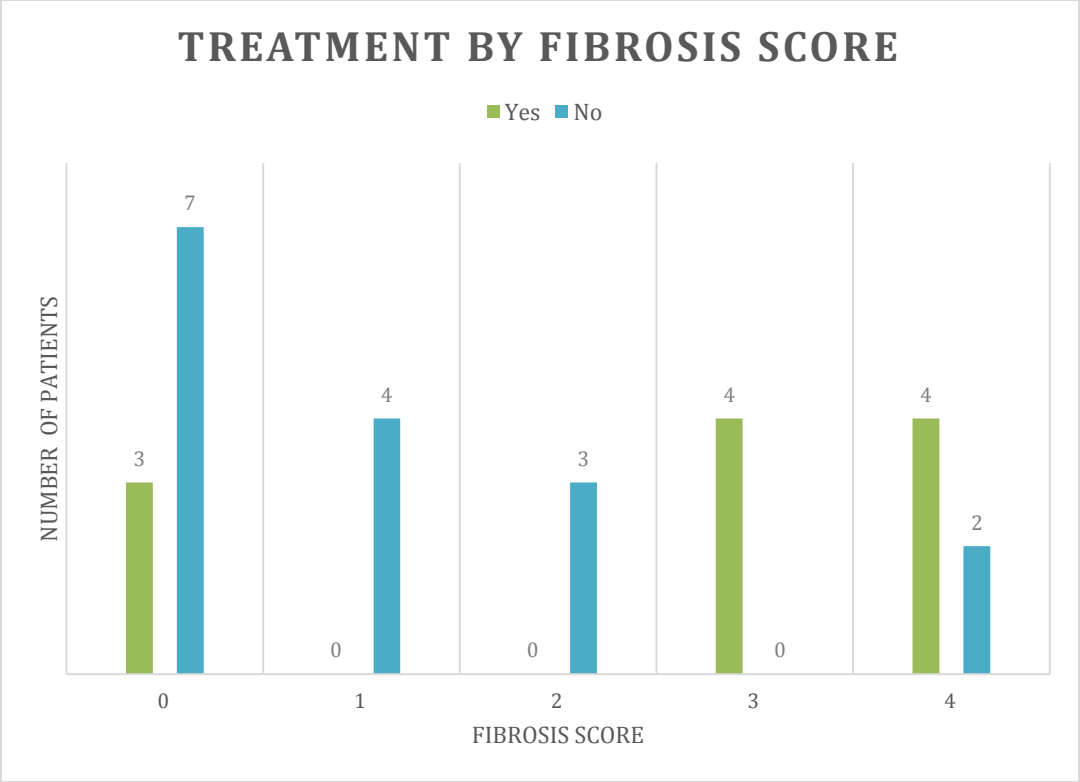

Figure 2. Number of patients either 1) Treated or 2) Not Treated based on fibrosis score of 0, 1, 2, 3, or 4. Most patients remained untreated until they reached a fibrosis score of 3 or 4.
Note: 2 of 3 patients in the treated category with a fibrosis score of 0 were on private insurance, and the third was on a sliding scale fee. (n=27)

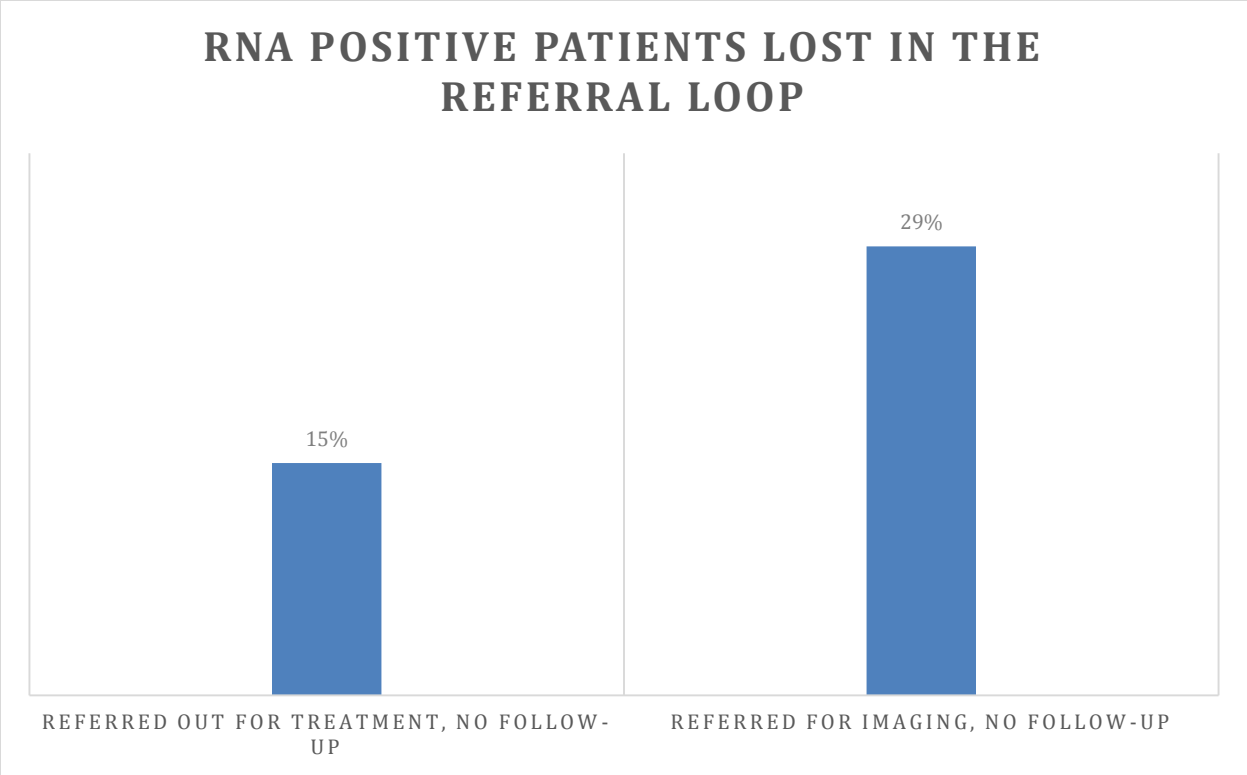

Figure 3. Percentage of patients who had a positive RNA lab result and were lost in the referral loop. 15% of patients who had a positive RNA test were lost in the referral loop when they were referred to a specialist for treatment, and 29% of patients who had a positive RNA test were lost in the referral loop when they were referred out for imaging tests for hepatitis C diagnosis. (n=55)

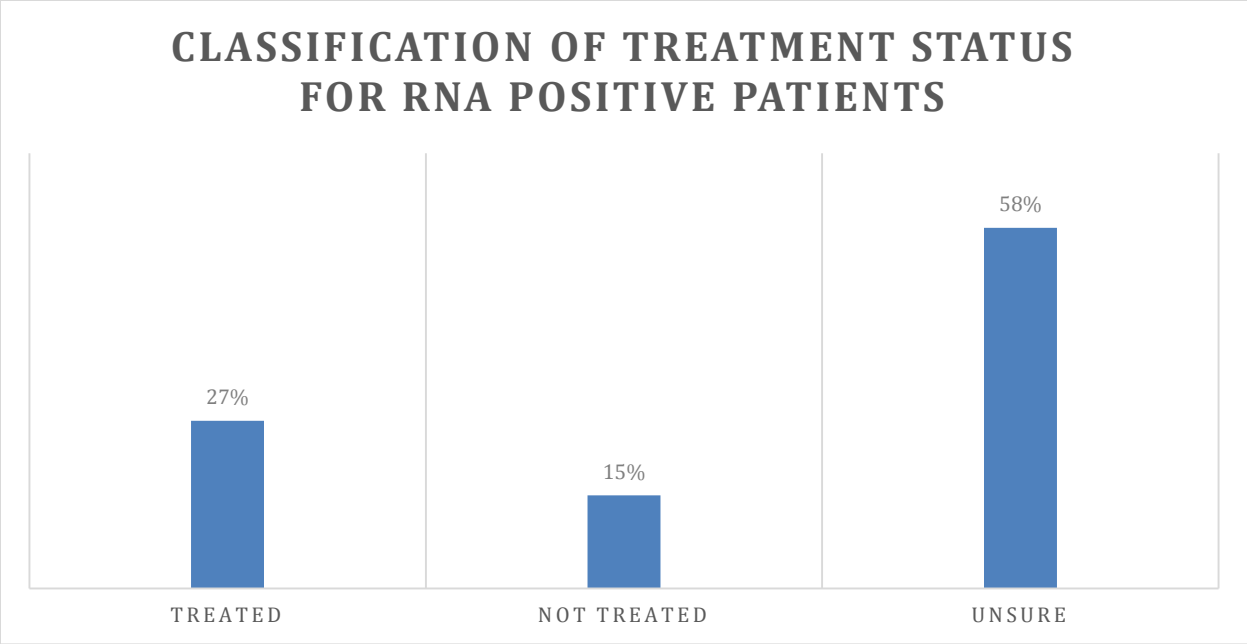

Figure 4. Percent of RNA positive patients in the treatment categories of: 1) Treated, 2) Not Treated, or 3) Unknown as informed by provider notes in patient electronic medical record data. (n=55)