

A Retrospective Study on Hepatitis C Virus Infected Individuals Lost to Follow-Up in Ticino: The Hub and Spoke Approach

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Abstract

Background: Approximately 71.1 million individuals are chronically infected with hepatitis C virus (HCV). The global incidence of HCV was 23.7 cases per 100,000 population in 2015, with an estimated 1.75 million new HCV infections diagnosed in 2015. In Switzerland, it is estimated that 37,000 patients have chronic HCV infection. In the Southern part of Switzerland liver disease patients are mainly followed at the six outpatient clinics of Epatocentro Ticino (EPT) connected with its hub in Lugano. The aim of the study was to identify lost to follow-up patients and reconnect them to specialist care. Methods: We used the database from EPT to identify HCV positive patients, who were lost to follow-up in the years 2007-2017. We consider lost to follow-up patients who had their last visit more than 2 years before closing date of analysis. We contacted the patients on the phone or by mail. Results: Overall 1271 patients have been at EPT between 2007 and 2017; of those 74 were lost to follow-up at the time of our screening. We received an answer from 60 of them. The results we collected were that 12 (6%) have died, 31 (42%) were currently followed by the General Practitioner (GP) or a different specialist, 9 (12%) were cured from HCV infection and did not need any further visit, and 4 (5%) refused to come for a check-up visit. In total, we rescued 4 (5%) patients and follow them at the EPT. Conclusion: Our look-back study revealed that our "Hub and Spoke-approach" had a high retention rate such that only 6% of our HCV patients were lost to follow-up. The look-back effort was still useful: the number of patients to recall identifying one patient needing treatment was 19.

Keywords

Hepatitis C, Follow-Up, Hepatocellular Carcinoma, Elimination of HCV, Epatocentro Ticino

1. Introduction

Hepatitis C is a global health problem; approximately 58 million individuals are chronically infected with hepatitis C virus (HCV), with about 1.5 million new infections occurring per year. In 2019, WHO estimated approximately 290,000 deaths for hepatitis C, mostly due to hepatocellular carcinoma and cirrhosis [1].

HCV is a chronic disease in 75% of cases, only 25% of the patients eradicated the virus without needing a specific treatment.

Chronic hepatitis C could lead to cirrhosis in 20% - 30% of patients, which often takes decades to manifest itself. Moreover, hepatocellular carcinoma could follow cirrhosis and be lethal for the patient.

The true incidence of hepatitis C in Switzerland is still not known, but the Federal Office of Public Health has recently estimated around 40,000 chronic infections national wide [2]. An observational, multicentre study on HCV micro elimination strategies, collected data from Geneva, St. Gallen and Zürich and found HCV prevalence between 0.5% - 0.7% and located 70% of the infected population in the age range from 30 to 64 years old [3].

Although its incidence is expected to decrease in the next decades, HCV-related morbidity and mortality are projected to increase by 2030. Most of HCV infections (approximately 80%) are bond to become chronic, with the aging of the affected population and the late-stage liver diseases, the patients often require costly healthcare procedures. It is thus easy to imagine that the above-mentioned conditions represent a social and economic burden for Switzerland [4].

In late 2017, Switzerland took an important step towards elimination by including patients independently of their fibrosis stage for reimbursement by the health insurance. According to the Swiss Hepatitis Strategy, being the diagnostic techniques improved, and patients successfully treated, HCV-related hepatocellular carcinoma could be reduced by 95% by 2030 and liver-related deaths could be reduced by 100% in 2030 [3] [5] [6] [7].

Epatocentro Ticino is a group practice serving the Southern Canton of Ticino, Switzerland with its 380,000 inhabitants. Ten specialists working at the Epatocentro Ticino are mostly Internists and hepatology specialists. It initiated its activity in 1999. It follows a hub and spoke approach working in close contacts with general practitioners' in locations distributed throughout the Canton. Approximately 1270 patients are followed at Epatocentro Ticino for HCV infection, the vast majority is infected with genotype 1 HCV, and currently 7% are undergoing specific treatment. Almost half of our patients (30%) present a severe liver fibrosis or cirrhosis.

The present study describes our look-back effort to identify and treat patients that were lost to follow-up. This is part of the above mentioned nationwide effort that aims at eliminating Hepatitis C in the next ten years to prevent HCV-related complications or late-stage liver disease from happening.

2. Materials and Methods

The study was conducted at Epatocentro Ticino from 2017 until 2020.

We consider lost to follow-up patients who had their last visit more than 2 years before the beginning of the study.

We employed our database to look for all HCV infected patients. The selection process consisted of looking into the database either computer or paper clinical records) who were lost to follow-up between 2007 and 2017.

In the database query, we included all HCV antibody positive patients, who had their records registered at the Epatocentro Lugano. The database was established at the beginning of 1999.

In this study, we identified and contacted lost to follow-up patients on the phone or via mail. All patients received a phone call or a letter in case they did not answer the phone. We asked the contacted patients whether they have scheduled follow-up with their practitioner or a specialist, or they currently take or have taken in the past any medication for HCV infection.

In case they were not in a doctor care, and were willing to, we fixed an appointment with a specialist at Epatocentro Ticino to check the disease stage and propose a treatment, when needed.

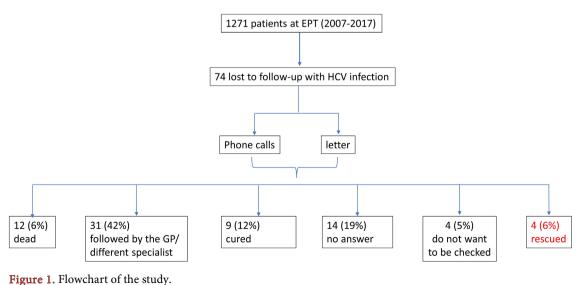
Patients who did not answer the phone or letter were categorized as untraceable and excluded from the analysis.

If deceased, we have recorded the date of death and asked the general practitioner if the cause of death was related to HCV end-stage liver disease.

We calculated the number of patients lost to follow-up and deceased; we then calculated the percentage of patients who answered to our call, the ones rescheduled for a visit and the ones who did not accept a further follow-up.

3. Results

Figure 1 shows the flowchart of the study; we identified 74 patients lost to follow-up with an HCV infection. Of these, we reached 35 patients on the telephone and 39 by mail or e-mail. Twelve patients (6%) were deceased; 31 (42%) were followed-up by other specialists or the attending physician, and nine patients



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(12%) were cured. Four patients (5%) were not interested in being followed by a doctor, and fourteen (19%) never answered to our mail or telephone calls. Among the contacted patients, though, four (6%) returned to the outpatient clinic at Epatocentro Ticino and were treated.

4. Discussion

The aim of this study was to identify HCV patients lost to follow-up, who had their last visit more than 2 years before the beginning of our study. The goal of re-contacting all patients who did not come to the scheduled checks for two years, is embedded in the wider goal of HCV elimination program within 2030 and, in the belief that chronic patients should be thoroughly followed. In fact, not only shall we promote a wider screening of the population in order to be aware of the infection, but also establish a chronic care, after the patient's cure and HCV eradication.

The currently available Direct-Acting Antivirals have an excellent cure rate with only mild side effects. The use of these drugs has increased in the past decade, and eradication is now possible, in non-resistant HCV viral strand; patients taken in charge from a specialist might benefit from these new generation drugs, but would need a tight follow-up.

With the new drugs and the goal of HCV elimination, we intended to find all lost to follow-up patients and offer them a treatment if needed. We were able to identify and treat four patients, who received specific care and would otherwise be lost and not cured. Due to the high adherence to the therapy, the number of untreated patients we found was small. In fact, data published by Helsana, a major Health Insurance Group in Switzerland shows a four times higher prescription of Sofosbuvir in the period of August 2014, the moment of its introduction on the market, until December 2015 in the Canton Ticino compared to the rest of Switzerland [8].

At Epatocentro Ticino, all remaining 1197 HCV infected patients are tightly followed with scheduled appointments. Follow-up of patients once they are treated and their Hepatitis C Virus is eliminated, includes regular checks, especially of those patients that have an F3 or F4 stage liver fibrosis; another group of highly monitored patients are those who have comorbidities and high risk to develop an HCC, and/or progression of their liver disease. Upon this topic, relevant guidelines valid for Switzerland have been published [9].

This study had few limitations; firstly, it is a retrospective, observational study and we included patients who were attending Epatocentro more than fifteen years ago, therefore some patients have changed address or telephone number and it was hard to connect to them.

Secondly, the sample size is rather small; we did luckily have only few lost to follow-up, which might be due to the spoke and hub approach.

Our study demonstrates the importance of periodic search of the lost to follow-up patients, not only for chronic hepatitis, but also for all diseases that might lead to severe comorbidities and are burdened by a high mortality. All medical doctors should periodically call all lost to follow-up patients and integrate them in the chronic care.

Because of this project, we were able to re-connect and explain to the patients the importance of treatment and periodic check-in. Moreover, those four rescued patients suffering from chronic hepatitis C were treated and re-allocated in a chronic cure program, and hopefully avoid the progression of the disease.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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