

## Experience in managing action research on hepatitis C survey in the prison community

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**Abstract** *We aimed to report the experience in managing action research on hepatitis C investigation in the prison community in the Triângulo Mineiro region, Minas Gerais, Brazil. The proposal was developed from March 2019 to March 2020, reaching 240 people to contain the spread of the disease through a survey, testing, and monitoring of positive cases. We adopted intersectoral action with articulation between Universities, Medical Society, Teaching Hospital, and State Secretariat for Justice and Public Security. Strategies for the management of action research are described: study settings and stakeholders, registration and formalization of the activity, application of tests, and management of reagent inmates. We identified difficulties regarding the accommodation of routines among the research team and the proper functioning of the penitentiary, which required extensive training between the parties and managerial articulations. We consider that the report collaborates with the organization of future research aimed at accessing this still invisible population, the prison community when it highlights the strategies adopted to conduct the research.*

**Key words** *Liver cirrhosis, Prisoners, Health promotion, Outcome and process assessment in health care*

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## The importance of containing the spread of hepatitis C in the prison community

Chronic hepatitis C virus (HCV) infection is a global public health problem that has led the World Health Organization (WHO) to set elimination targets by 2030, which include the diagnosis of 90% of individuals living with HCV, making direct-acting antivirals available to 80% of those who are eligible for treatment and reducing incidence by 90%<sup>1</sup>. According to the WHO, more than 70 million people are infected with HCV worldwide. In Latin America, the population infection frequency range from 1.5% to 3%. In Brazil, more than 1.1 million people are assumed to have acquired the infection, and more than 700,000 would have an active infection. Hepatitis C is, in fact, the most common cause of end-stage liver disease requiring liver transplantation in the country. The burden of HCV infection has led Brazil to be one of the signatories of the WHO policy for eliminating HCV by 2030<sup>2</sup>.

HCV is a severe health problem in prison institutions. As injectable drugs easily transmit it, individuals with substance use disorders are often incarcerated. There is a disproportionately high prevalence of HCV in correctional facilities compared to the general population. New transmissions are also high due to insufficient access to harm reduction measures in those locations. More than 10 million people worldwide spend time in prisons and other closed environments each year, most of whom will return to the community. Therefore, incorporating prison institutions into HCV elimination plans will reduce the infection burden in correctional settings and neighboring communities<sup>3</sup>.

High infection rates in prisoners and the substantial risks – such as cirrhosis and hepatocarcinoma – associated with untreated chronic hepatitis C emphasize the importance of HCV screening and access to treatment in prisons. Thus, WHO recommends testing all prisoners for HCV<sup>4</sup> infection. In Brazil, a systematic review on HCV in the prison population published in 2015 found an overall prevalence of 13.6%, with the lowest prevalence detected in Espírito Santo (1.0%) and the highest (41.0%) in the state of São Paulo<sup>5</sup>. A recent study found only a 0.2% prevalence of HCV antibodies in the region of the country that concentrates the most significant number of prisons (west and northwest of the state of São Paulo). However, data were obtained through a questionnaire sent to each penitentiary health unit (28 prisons), and the prevalence of in-

fections estimated by the questionnaire may not be accurate enough<sup>6</sup>.

Above all, the situation of testing and monitoring underpins complex actions for its effective performance, such as access to the prison community, given the involvement of many institutions, including the Public Security Secretariat, the Judiciary System, and the Prison Directorate, Health Secretariats. Ideas for possible solutions were discussed.

Faced with this reality, with the assistance, public security, and even the scientific community, doubts still hover on how to organize and manage research projects that impact the implementation of care actions, health promotion, and disease prevention for the prison community. For this reason, it is crucial to invest in the dissemination of ways about health and human rights in Brazilian prisons among populations still invisible in studies. The first steps of a complex subject are described, the organization of this experience in the Triângulo Mineiro region of Minas Gerais, Brazil, reporting on the implementation of intersectoral articulations to diagnose viral hepatitis and the treatment in the prison community. In this sense, this study aims to report the experience in managing action research on hepatitis C survey in the prison community.

### Strategies for managing action research on hepatitis C survey

This is a report and critical analysis of the experience of entering the walls of a prison institution to sensitize as many inmates as possible about Hepatitis C, its transmission modes, and its complications when untreated. Moreover, the project consisted of applying a questionnaire in search of possible risk factors for infection in the prison community, carrying out the rapid test and monitoring.

The action research was based on the Ministry of Health's National Plan for the Elimination of Viral Hepatitis, a signatory to the WHO proposal to eradicate viral hepatitis from the planet by 2030. The Brazilian Society of Hepatology and the Brazilian Liver Institute supported the action research project in its design. It is worth noting that the Brazilian Institute for Liver Studies (IBRAFIG) launched the national campaign "We cannot leave anyone behind" to encourage the diagnosis of viral hepatitis and fulfill the goal of eliminating the disease. Thus, mobilizing medical and civil societies on the importance of testing and treating these viruses in populations considered at high risk.

Regarding the Triângulo Mineiro region of Minas Gerais, the mobilization for action research that included testing and treating people deprived of their liberty was conducted under the guidance of the Program for Expanding the Diagnosis of Hepatitis C at the Hepatitis Outpatient Clinic of the Hospital de Clínicas of the Triângulo Mineiro Federal University (HC-UFTM).

### Study setting and stakeholders

The HC-UFTM Hepatitis C Diagnosis Expansion Program has been carrying out research, teaching, and extension projects since 2014 to diagnose and offer treatment for Hepatitis C in the macro-region of the Southern Triangle of Minas Gerais and train PHC teams to identify risk groups and receive individuals reactive to anti-HCV. More than 30,000 people have been tested since, with a prevalence of 0.7% of the antibody against HCV<sup>7</sup>.

In 2019, the team turned to the groups in which the elimination of the virus tends to be challenging, including those in the prison system. As Uberaba, UFTM's headquarters, has a state penitentiary that housed 1,564 inmates and 220 employees at the time, the unit, through its director of Assistance and Resocialization, was invited to participate in the project.

Three professors were part of the research team (two from the medicine course and one from biomedicine), two nurses (one epidemiologist), a resident doctor in gastroenterology, four students from the biomedicine course, three from Medicine, and two from nursing. Teachers, professionals, and students from three higher education institutions in the city were strategically invited, namely, UFTM-public teaching institution, the University of Uberaba, and FACTHUS – private institutions, to promote the expansion of the Hepatitis C Diagnosis Program in the municipality. The components from the UFTM had already been working on the Hepatitis C Diagnosis Expansion Program since 2014. The Unified Health System (SUS) provided the test supplies in a programmed action to reduce the incidence of Hepatitis C.

### Recording the activities

Initially, a questionnaire was developed based on the one used by Harnólido Coêlho in a penitentiary in Ribeirão Preto/São Paulo<sup>8</sup>. This tool was created to search for risk factors for the transmission of the Hepatitis C virus, which have

been described in the specialized literature as necessary for individuals deprived of their liberty<sup>8-10</sup>.

The variables included were the date of birth; marital status; whether to have children or not; place of birth and residence upon arrest; schooling level; having been previously incarcerated and for how long; having had a sexually transmitted infection; having a tattoo or piercing; having already received blood transfusions or products; having already worked in places at risk for the transmission of the virus, such as hospitals, pharmacies, among others; be known to have HIV or HBV; having already undergone hemodialysis; having someone in the family with hepatitis C; having already undergone surgeries, including dental and number of procedures; having been homeless and for how long; using or having used injecting drugs or not; sexual preference; use of condoms; receiving or not receiving intimate visits; the number of sexual partners in the year before the arrest; drinking alcohol and volume; and being a smoker. An Excel spreadsheet was built to enter all the data collected so that each questionnaire applied became a number to maintain the respondents' confidentiality. The variables were inserted so that the statistical analysis could be performed later.

The action research generally aimed to analyze the prevalence of HCV and social, clinical, serological, and molecular biology aspects among the population deprived of liberty and public security professionals in Uberaba. The specific objectives were to estimate hepatitis cases at the local level (study setting); to identify socio-epidemiological aspects among inmates and public security professionals that could emerge as factors associated with the disease; to map prevalent genotyping and reinfection cases; to determine the staging of liver fibrosis, the diagnosis of cirrhosis and its complications; to identify associated comorbidities and co-infections.

### Formalizing the activity

The action research project and the questionnaire were sent to the State Department of Justice and Public Security (SEJUSP) – Research and Extension Center in July 2019, together with the request for authorization to conduct the study. SEJUSP sent the SEAP Resolution N° 59 of June 14, 2018, to the team, establishing criteria for conducting research within the State Prison Administration Secretariat. Moreover, each researcher was asked to send the following docu-

ments: Disclaimer – use of images/audio; Term of commitment regarding any changes in the project, Research Request Form at SEJUSP, with data from the researcher, reference data; Declaration of the educational institution (the data referring to the course, the researcher and the proposal for the intended type of research must be included); Identity card, Individual Taxpayer Number (CPF), Document of the vehicle to be parked in the penitentiary yard; Follow-up form on the research project, with data about the researcher and the research. Furthermore, the requirements for entering the place, from clothes to be used, presentation at the entrance, meeting places, days of the week, and available times were informed.

The procedures for project approval by the Research Ethics Committee of the HC-UFTM, submitted to Plataforma Brasil, were initiated after receiving the letter of consent that allowed conducting the research signed by the Superintendent of the Public Security Observatory of the Undersecretariat of Intelligence and Integrated Action, SEJUSP, in the State of Minas Gerais. In compliance with the Declaration of Helsinki and Brazilian ethical standards, the case reported was approved by the Research Ethics Committee of the Triângulo Mineiro Federal University under resolution n° 466/2012, addressing human research (opinion n° 3.918.981).

The undergraduate and graduate students linked to the project were trained regarding their behavior during the interviews; the relevance of the variables studied and care with the approach concerning intimate individual issues; the importance of the language adopted to guide the inmates about the disease and its risks; and the current facilities regarding the diagnosis and treatment of infection in Brazil.

#### **The application of questionnaires and tests and management of inmates reagent for anti-HCV**

The visits were previously scheduled and should always coincide with the sunbathing time of each pavilion, so it was the correctional officers who chose the pavilion to be visited. The researchers presented themselves at the penitentiary entrance and, after individual identification, an agent took them to the review room. No researchers were searched; everyone passed through the metal detector, and the group was led to the infirmary.

With the tests and questionnaires in hand, they were conducted by the nurse and escorted

to the pavilion determined by the agents. In the pavilion, the classroom attached to the courtyard was prepared to receive researchers and prisoners. One of the agents announced the presence of the researchers, and one of them invited the prisoners to the research with a brief explanation next to the patio railing. Interested parties formed a line at the gate and were taken one by one to the room, where they were instructed in detail about research, ways of transmitting the virus, the importance of the disease, and its complications. In case of acceptance, the informed consent form was carefully read, and signatures were collected.

The rapid test was performed at the end of the interview. The result was not disclosed immediately so as not to cause embarrassment among cellmates. The mean time spent with each inmate was 30 minutes. The researchers had about two hours per day time to conduct the project. The number of inmates approached depended on the number of researchers present at each visit. The research started in December 2019 and was suspended in March 2020 due to the COVID-19 pandemic. Thus, in four months, only 240 inmates and no correctional officers were tested – as they did not accept the research.

Five (2%) of the 240 people deprived of their liberty tested for hepatitis C in the period were positive. None of them could leave the penitentiary to continue investigating and treating the infection during the first year of the pandemic. The institution's rules determined that if an inmate had to leave, he should stay in isolation for 14 days when he returned, preventing sunbathing. Therefore, only prisoners with acute symptoms of illness would be referred by the local health team to an emergency unit of the Unified Health System (SUS). Visits to determine fibrosis staging, genotyping, or viral quantification in anti-HCV reagents are ongoing due to suspensions of outpatient care imposed by the COVID-19 Pandemic (Figure 1).

As the first steps in the cascade of care, screening and confirmation of chronic HCV infection are essential to ensure that individuals are aware of their HCV status. Virus screening in correctional settings is not only complicated by a lack of knowledge related to the infection, but incarcerated individuals often do not provide a complete history of injectable drug use due to the associated stigma and fear of discrimination. Thus, universal HCV exclusion testing at the entry to correctional facilities can help mitigate stigma by making testing routine and raising

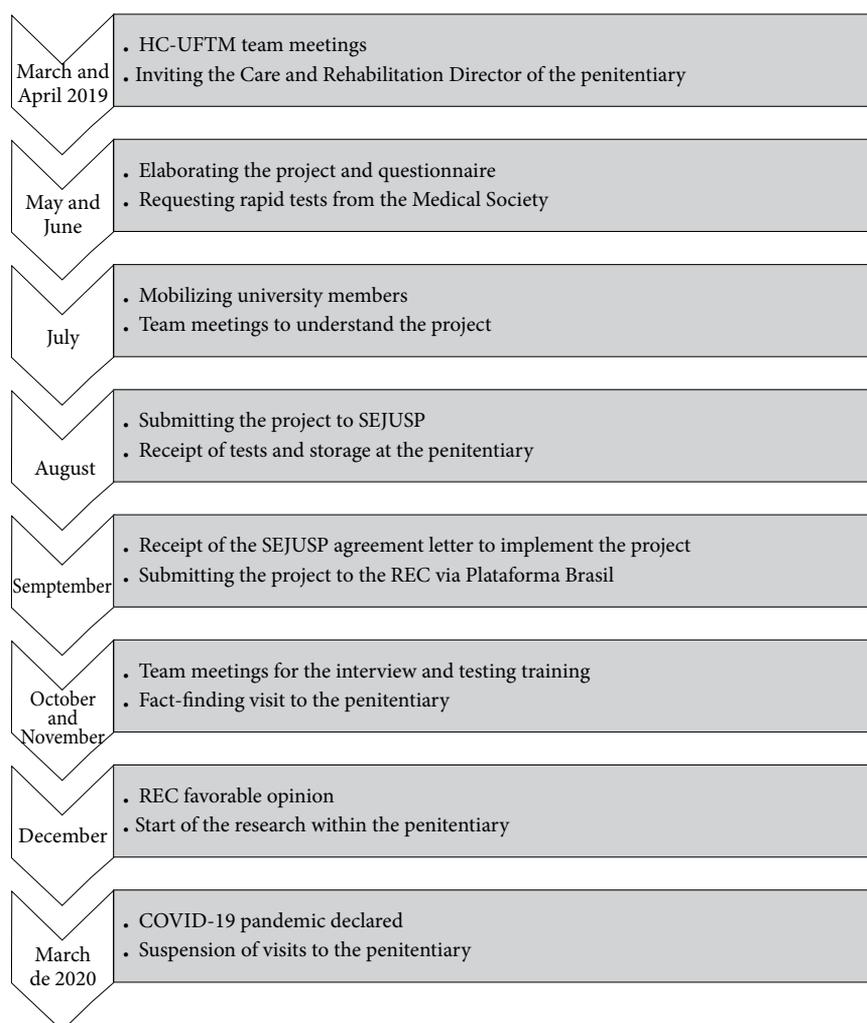
awareness of HCV infection. Treatment can be challenging for individuals who are diagnosed. In general, correctional facilities have even less access to medicines, even in rich countries<sup>11,12</sup>.

### Final considerations

Prisons provide a relatively stable environment for diagnosing and treating hepatitis C, as they generally have a physical and staffing structure in the health area and are organized around their routine. We should emphasize challenges in conducting research with the prison community, which permeate from the institution's operating rules, availability of correctional officers

and health staff for monitoring, adequacy of the project and submission to the bureaucratic procedures of the research, the ostensible training of the teams of researchers, and setting to conduct the process better.

Primarily, the interventions were designed to maintain the safety of the research team. It is stated that the penitentiary does not allow interviews and tests on weekends and holidays or at night and meal times. Some interferences in prison daily life delayed or canceled interviews/testing. One of these reasons was the lack of correctional officers and nurses for follow-up. As university students were part of the team, it was crucial to articulate the academic agenda, class periods, and the conduct of action research.



**Figure 1.** Strategies for managing action research. Minas Gerais, Brazil, 2021.

Improved access to health services, which includes HCV screening, treatment, and linking to care strategies facilitated by pre-release planning and post-release transport, will ensure that no inmate is “left behind”. Since the prevalence of the hepatitis C virus remains high, with low adherence to treatment, strategies for special groups must be well designed. In general, this report, a local study conducted in a penitentiary in the

Triângulo Mineiro region of Minas Gerais, Brazil, collaborates with the organization of future research aimed at accessing this still-invisible population in studies, namely, the prison community, when it highlights the strategies adopted to conducting the research and the difficulties faced. We suggest developing future research that presents the survey results as the existing risk factors in this analyzed community.

## Collaborations

GPM Gomide: project conception, design, analysis, and interpretation of data; writing the article and final approval of the version to be published. MS Teixeira and GA Pereira: project design, data collection, writing the article, and final approval of the version to be published. FC Camargo: data analysis and interpretation, relevant critical review of intellectual content, structuring the work method, final approval of the version to be published. BG Pastori, FF Dias, JCC Ferreira, NC Silva, OS Carvalho Neta, PT Meireles, VGS de Lima and RAP Cunha: data collection and presentation of essential suggestions for the development of the work. LZ Piccoli: data analysis and interpretation; writing the article and final approval of the version to be published. DR Abdalla: project conception, relevant critical review of intellectual content, final approval of the version to be published. CCHB Oliveira: project design, design, analysis and interpretation of data, relevant critical review of intellectual content e final approval of the version to be published.

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Article submitted 20/11/2021

Approved 06/06/2022

Final version submitted 08/06/2022

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Chief editors: Maria Cecília de Souza Minayo; Romeu Gomes, Antônio Augusto Moura da Silva