

The Hepatitis C Case Registry: A Major Advance in Understanding and Improving Hepatitis C Care in VA

Sophia Chang, MD, MPH
Center for Quality Management in Public Health



Key points

- The Hepatitis C Case Registry is a milestone in efforts to improve hepatitis C care in VA.
- The Registry captures information on every hepatitis C patient (by positive test or diagnosis) in the VA system between 1996 and the present.
- Early results show that over 215,000 patients with hepatitis C infection have been cared for in VA since 1996.
- Over 180,000 of patients in the Registry were cared for in the VA system during fiscal year 2002.

Background

As a nationwide medical care system with over 160 medical centers and more than 800 outpatient clinics, the Veterans Health Administration is a large and complex organization. Understanding and managing a system of this magnitude requires modern and efficient data management. Although there are many sources of data related to patient care in VA, until recently there was no single source for comprehensive information specifically about patients with hepatitis C and their care. The creation of such a database has been a priority since responsibility for hepatitis C in VA was given to the Public Health Strategic Health Care Group. The launch of the Hepatitis C Case Registry is a milestone in efforts to better understand and to improve hepatitis C care in VA. The information in this briefing is the first public discussion of results gathered through the registry.

The aim of the Registry is to enable VA clinicians and administrators to:

- Identify all VA patients who test positive for Hepatitis C antibodies or have a recorded diagnosis of hepatitis C
- Monitor specific elements of medical care for these patients
- Review the clinical status of hepatitis C patients, including the outcomes of hepatitis C treatment antiviral treatment, across the VA health care system
- Identify opportunities for improving quality and efficiency of care.

In order to protect patient confidentiality, the national data reporting system does not contain information that would identify individual patients. All national reports from the system will combine data at the national, VISN, or facility level.

The Registry has three components:

1. *Hepatitis C Case Registry Software:* This software—which is used to capture patient data—was developed and programmed within VA and released in May 2002. By September 2002, the software was installed at all 128 data-reporting VA stations across the country, with live and web-based training offered to designated registry coordinators at each station. Once installed, the software automatically created each station's local registry list, using data from the electronic medical record system on veterans with hepatitis C back to January 1, 1996. The system is automatically updated nightly, to include new information about patients already on the local registry list, and to add new hepatitis C patients. The system also enables health care providers to produce their own reports (such as the local registry list, the list of patients on hepatitis C treatment, and data error reports), to correct errors as necessary, and to monitor the use of investigational drugs.

2. National Hepatitis C Case Registry Database: Every night, selected data from the individual facilities are transmitted directly into the national Hepatitis C Case Registry database. Information sent from the stations is combined each month with outpatient and inpatient data from the VA's National Patient Care Database. From this merger of two national databases, it became possible to start producing preliminary internal reports in November 2002. As these reports are generated, continual feedback is given to the reporting stations to improve the quality of the data (e.g., correction of erroneously entered or coded information). The National Database is the source of preliminary results described in this presentation.

3. CPRS (Computerized Patient Record System) Hepatitis C Reports: This component is planned for release in 2003. CPRS is version of the electronic medical record used by most clinicians. The new Hepatitis C Reports function will allow health care providers to use their local hepatitis C registry list in the management of hepatitis C patient care. Providers can evaluate care for a group, or population, of patients, rather than relying on chart review, one patient at a time. For example, the report would allow a clinician to produce a list of all his or her hepatitis C patients with abnormal liver function tests, or those who have failed to refill a prescription for their hepatitis C treatment on time. These types of reports will help providers identify weaknesses in their local systems of care and help them improve the timeliness and quality of care provided.

Early results from the National Registry

Based on our preliminary analysis of this new national database, over 215,000 patients with hepatitis C infection (as defined by a positive blood test or a documented diagnosis) were cared for in the VA health care system between January 1996 and February 2003, and are included in the Registry. These patients are further characterized as follows:

- Ninety-seven percent are male.
- The average age is 53 years
- Approximately 10 percent of patients in the Registry have died (from any cause)
- Over 180,000 of these veterans were seen during fiscal year 2002.
- During FY02, Hepatitis C Registry patients had a total of over 90,000 inpatient admissions and over 3.5 million outpatient visits.

Of the over 215,000 hepatitis C patients listed in the registry, 63% are over the age of 50. Among those with documentation of era of service, two-thirds first served during the Vietnam era. Fourteen percent have some degree of service connection for any condition. Over 29,000 liver biopsy results and over 9,000 autopsy records are recorded in the registry. As we are able to examine this information, we will get a more detailed picture of the impact of hepatitis C among veterans in VA care.

Why are the numbers larger than those previously reported?

The differences result primarily from the way "hepatitis C patient" is defined and how such patients are identified using available sources of information.

Previous reports of the numbers of hepatitis C patients receiving care in VA facilities were based on administrative datasets developed primarily for fiscal and resource allocation purposes. In the Hepatitis C Case Registry, which is primarily a clinical tool, the process of identifying patients is meant to cast a wide net so as not to miss anyone who is infected. Therefore, the software automatically picks up all hepatitis C diagnoses (including erroneous entries) and any positive hepatitis C antibody results (which will include false positives or patients who are subsequently able to clear the virus). The software, however, enables the facilities to correct or delete these entries in order to make the Registry more accurate and useful.

Future work

As of this writing, the Hepatitis C Case Registry is undergoing systematic data quality review by reporting stations at VA medical facilities. Those station data are combined with utilization data (such as clinic visit and procedure codes) from other national VA systems, particularly the National Patient Care Database. As with any large database, cleaning, validating, and troubleshooting are a constant feature required for maintenance of accuracy and quality, but are especially time- and labor- intensive at initiation. Thus, the data presented here must be considered preliminary as we keep doing the important work of assuring that the first numbers reported are accurate. We anticipate that generation of regular, validated, accurate reports by the end of FY03.

The VA Hepatitis C Case Registry will be an invaluable tool for the Department of Veterans Affairs' program in hepatitis C. The Hepatitis C Case Registry was designed to track the experience of veteran patients with hepatitis C infection and to provide clinicians and managers with the information they need to plan and deliver efficient and high-quality care.

