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**Objective:** The objective was to identify and treat segments of the local population at greatest risk for viral hepatitis C (HCV) infections.

**Design:** The tribal-based HCV initiatives included community involvement and outreach and HCV data were mined and analyzed. Medical records were reviewed, and new HCV tribal health policies and procedures were developed.

**Results:** A total of 251 tribal members (63.7% male) were diagnosed with HCV and had a positive confirmatory test between the years 2009 and 2014. Through community-based outreach efforts, 85 HCV patients were successfully contacted for education, field-testing, referral and follow-up, an increase of more than 300%.

**Conclusions:** The tribe increased ways to monitor HCV risk factors and communicable disease pathways. *Ethn Dis.* 2018;28(4):549-554; doi:10.18865/ed.28.4.549.

**Keywords:** American Indian; Hepatitis C; Capacity Building; HIV/AIDs; Rural Health

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## INTRODUCTION

Viral hepatitis C (HCV) takes a greater toll in American Indians compared with the general US populations. The American Indian and Alaska Native (AI/AN) rate for HCV is 1.32 case per 100,000 population.<sup>1</sup> The mortality rate for HCV among AI/AN is 2.3 per 100,000 compared with 1.7 per 100,000 in the general US population.<sup>2</sup> From 1998-2008, an average of 7,514 HCV cases were reported each year<sup>3</sup> and the average age of HCV diagnosis was aged 44 years.<sup>4</sup>

In 2013, a southwest tribal Health Services Division (hereafter referred to as HSD) undertook a project to identify and treat segments of the local American Indian adult population at greatest risk for HCV infections. Typically, the tribe refrains from recognition of HCV infections due to potential stigmatization. This project works toward the World Health Assembly resolution and the US goal to eliminate viral hepatitis as a major public health problem by 2030.<sup>5</sup> HCV infection is the most common chronic blood borne infection in the United States, with an estimated 2.7 - 3.9 million Americans infected.<sup>6</sup> Within Arizona, it is estimated that there are 80,000

residents living with HCV, with more than 10,000 cases reported each year.<sup>3</sup>

The HSD is an entity managed by a federally recognized tribe. The majority of tribal members (90%) lives within Arizona, 51% are females.<sup>7</sup> Only 2.2% of tribal members have a college or professional degree and 36% of the reservation population live below the poverty level. The tribal community suffers an 86% premature mortality rate and die 19.5 years younger than Whites in Arizona.<sup>8</sup>

Poor socioeconomic conditions, current or former injection drug users, and high rates of sexually transmitted diseases have been associated with increased prevalence of HCV<sup>4,9</sup>; these are characteristics of the HSD tribal population.

The purpose of this article is to describe HSD's experience to expand and nurture HCV treatment and prevention capacity while building infrastructure. A surveillance system was established, validated by medical records, and HCV tribal health policies and procedures established. Existing programs (ambulatory care, contracted health services, HIV/AIDS prevention, and a methadone clinic) developed and implemented culturally appropriate approaches to identify clients infected with or at

risk for HCV. In this article, we describe tribal-based HCV initiatives and illustrate how a southwest tribal government's efforts were successful in gaining greater control of patient care while maintaining tribal values in health systems management.

## METHODS

Methods to build HSD infrastructure included: point-of-care HCV testing; education; establishment of an HCV registry and policies; and case management.

HSD staff members from the Community Health Nursing, HIV/HCV and the Methadone Clinic programs were identified as critical personnel to assist with point-of-care HCV testing. The HCV testing was done both within the clinical setting and the tribal community. HSD collaborated with the local county health department for field-based HCV testing kits. Additionally, HCV testing was completed annually among all patients who were enrolled in the HSD methadone and needle exchange programs.

HSD staff members disseminated CDC educational materials and used some of the materials for one-on-one education sessions with patients and at-risk community members. Outreach was done at community events and at various tribal health department functions and gatherings (eg, community celebrations, health fairs). HSD staff members also provided harm reduction kits, condoms, female dams, and incentives for testing. The broader tribal community and high-risk individuals were active-

ly informed about HCV and HIV.

To establish the HCV Registry, the suite of health-related applications under the Indian Health Services (IHS) Resource and Patient Management System (RPMS) was utilized. RPMS is used by the HSD as the patient database system. RPMS

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was developed in the late 1980s by a collaborative effort between Indian Health Services and Veterans Affairs (VA)<sup>10</sup> and consists of more than 80 applications centered on one patient database. Taxonomies were created from International Classification of Diseases (ICD) diagnostic codes and Current Procedural Terminology (CPT) codes. The project team used both ICD-9 and ICD-10 codes (the conversion to ICD-10 codes occurred on October 15, 2016) to capture HCV patients coded with both ICD codes. These codes rendered

a subset of patients that was used to establish, track and case manage the subset. The project team verified HCV patients (Table 1) and eliminated duplicate patients so not to double count the same patient more than once. The comprehensive populating of the HCV registry involved consolidation of data from three other primary health databases including a contracted direct care system and a behavioral health care system. Systems of interfaces and data crosswalks were established to consolidate the data into one database.

Once the HCV Registry was established, the task to ensure integrity and data quality management was undertaken. A team composed of Community Health Nurses (CHN), Community Health Representatives (CHR) and Health Information staff (HIMS) reviewed health records of patients captured in the HCV Registry and listed patients as active or inactive based on records validation.

In conducting literature searches, there was a dearth of reference materials for tribal programs such as HSD. Information from the National HCV Testing Policy 2012<sup>11</sup> was referenced for the HSD local HCV policies and procedures. The resulting HCV policies and procedures included seven primary components: 1) overview of the program; 2) Indications; 3) Informed Consent; 4) Screening; 5) Testing; 6) Diagnostic Testing; and 7) Staffing. These policies and procedures were vetted internally and then presented to the HSD Policies and Procedures Committee for review and approval. The Committee approved the policies and procedures on September 7, 2015,

and were updated on April 13, 2016.

As part of quality care improvement and community outreach, nurses contacted HCV patients to review current medical conditions and to verify documented history, including medication lists and visits. Patients were contacted initially through phone calls to set up a home visit. If telephone contact was unsuccessful, a letter was sent. For those patients contacted, a HCV questionnaire was completed.

Outreach to community members with polysubstance use were made and included health education, screening, referral to detoxification and medical care scheduling. The goal was to establish baseline exams and labs for patients and to diagnose conditions earlier in the disease process.

Outreach also included expanding services. For example, HSD organized a mobile syringe exchange service in isolated areas of the reservation. HSD also engaged in patient navigation specifically for patients with low reading skills, illiteracy, and/or impairments. All outreach activities included the local native language and incorporated tribal beliefs and values. Traditional norms and knowledge were incorporated into education materials, videos and presentations.

## RESULTS

The expansion of publicly supported disease identification and treatment services and supports for HCV-positive clients have enabled an integrated, structured and reliable system for HSD's HCV continuity of care. Through these steps, the HSD

**Table 1. Frequencies of viral hepatitis C virus (HCV) infection among tribal members, by age and sex, 2009-2014**

Age, years	n (%)		
	Male	Female	Total
18-24	2 (1.3)	2 (2.2)	4 (1.6)
25-34	6 (3.8)	8 (8.8)	14 (5.6)
35-44	26 (16.3)	17 (18.7)	43 (17.1)
45-54	61 (38.1)	29 (31.9)	90 (35.8)
55-64	50 (31.2)	31 (34.1)	81 (32.2)
≥65	15 (9.4)	4 (4.4)	19 (7.6)
Total	160 (100)	91 (100)	251 (100)

has expanded capability and expertise to recognize and respond to public health threats and emerging health issues. For example, HCV policies, which had not existed, were enacted; the HCV Registry enabled outreach and identification of additional HCV patients; and dedicated HCV personnel increased with the addition of Licensed Practical Nurses (LPNs) and two Community Health Representatives (CHRs), thereby providing HCV patients with individualized treatment plans, assessments, care coordination, and support. These combined efforts built HSD capacity to assist patients with all aspects of their health care, ranging from medication adherence, personal care, and medical issues, to mental health care. In addition, HSD staff members provide escort and transportation to and from appointments, and educate patients before, during and after appointments. Using a holistic health care approach, the HCV/HIV team dedicate their time and energy to providing the best care possible to all patients served. The HCV interventions also included HIV-focus areas due to similar patient risk behavior profiles.

HSD formed strong partnerships to reach its goal of building capac-

ity and infrastructure to identify and mitigate future public health threats. Partners included: a regional health maintenance organization (HMO); the Indian Health Service (IHS); and the local county health department. The local HMO provided bi-monthly HCV clinics offering testing, maintenance and follow-up for a total of eight hours a month. The IHS provided the aforementioned RPMS and technical assistance for HSD's electronic health record system to allow for reliable health data, critical to epidemiology research and community health action. The county health department shared public health data, resources (including rapid HCV test kits), and epidemiologic data analysis.

CDC's Office for State, Tribal, Local and Territorial Support provided HSD with information on webinars, evidence-based policies, and technical support in developing practices and protocols for tribal response to HCV. The CDC's National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention was a partner for access to interactive tools including HCV data, trends and patterns.

The HSD project staff identified a total of 251 tribal members (63.7% male) who had had a positive con-

firmatory test and HCV diagnosis between 2009 and 2014 (Table 1). The mean age of patients was 53 years (range 18-81 years). These individuals are now active patients within the newly established HCV Registry and will be tracked moving forward for compliance with follow-up care. Through community-based outreach efforts, 85 HCV patients were successfully contacted for education, field-testing, referral and follow-up, in-

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creasing our patient outreach (n=28) in 2009 when the initiative began.

These tribal-based partnerships permitted local expansion of the use of evidence-based practices leading to more effective systems of care, data collection, information sharing, and coordination of care. For example, referrals are now received from within the tribal health programs, local HMO, local hospitals, methadone treatment programs, the Indian Health Service, urban health programs, and self-referrals. A more expansive system of care included case management with clinicians, social

services, housing, and transportation. Local community support networks expanded to include youth health services, an HIV task force, and an HIV prevention planning group. Large community gatherings were utilized as forums to educate the broader community and education booths were set-up at health fairs, wellness days, tribal recognition day, kick-offs, fun runs, vaccine clinics, and awareness days. Ongoing evidence-based continuing education for providers included Integrating Viral Hepatitis Into Your Work and STD Control. These trainings were conducted in collaboration with the local HMO, the county health department, the state department of health, and the local chapter of the AIDS Foundation.

## DISCUSSION

This HCV initiative was part of the tribe's vision to establish an infrastructure needed to expand capability to recognize and respond to public health threats and emerging health issues. Inherent in this HCV initiative were community involvement and outreach, which included meetings and activities with community members, representatives from the tribe's wide array of programs, other tribal departments, and city, county and state agencies. Extensive networking permitted the implementation of validated approaches, thus saving valuable time and resources. For example, HSD's partnership with the National Native AIDS Prevention Center provided access to culturally appropriate training and education on stigma, polysubstance use, and continuity of

care within a homeless context. Collaboration with the AIDS Foundation provided training on the prevention of opioid overdose and partnering with the county health department allowed us to provide field-based HCV testing. These approaches can be used by other tribes or rural health programs interested in establishing HCV surveillance and outreach.

HSD established baseline HCV data, HCV policies and procedures, internal auditing through hand surveillance systems, an HCV-specific registry, data-driven health care decision-making, and the integration of community-based evaluation into overall HCV patient care.

The HSD took its responsibility seriously for providing high quality HCV services and operated with business principles, balanced with personal and sensitive patient care. Quality improvement, ongoing process and outcomes evaluation, peer review and risk management were essential business practices for the described approaches.

In gathering standards and documentation of measures for HCV, the tribe utilized the 12 domains of public health<sup>12</sup> and increased ways to monitor HCV risk factors and communicable disease pathways. HCV was actively discussed within the tribe's Performance Management Plan, Quality Improvement Plan, Workforce Development Plan and Emergency Management Plan. These led to enhanced service delivery and revenue generation.

Future goals for the HCV initiative include implementing a Graphic User Interface (GUI) tool, iCare, developed by Indian Health Service,

which will provide a streamline application for the HCV Registry and other comprehensive patient care endeavors. The HCV team continues to meet on a regular basis to conduct registry reviews to validate entries and double-check queries. Updates on outreach efforts are provided and the team works together to establish best practices. The team has agreed to review the HCV policies and procedures on an annual basis, at minimum. The HCV team remains actively engaged in calculating annual costs of care for HCV patients.

The challenges and limitations to establishing tribal capacity were many. When working with sensitive diseases, such as HCV, there were inherent challenges in: accurately identifying the prevalence of a disease among tribal members who shy away from medical or mental health treatment; assessing the prevalence of behavioral risk behaviors throughout the population; and reaching individuals who might feel stigmatized and do not desire treatment. Some patients were ashamed of their diagnosis and were frightened of what family members or the community perceptions and reactions might be. The care of and outreach to HCV patients was complicated by comorbidities and acute situations such as seizures, withdrawals, overdose, and domestic violence. The outreach efforts included the tribal Emergency Medical Services and/or Police Department. HCV project staff members encountered safety issues for staff members during outreach due to hostile verbal and/or physical confrontation stemming largely from patients' lack of readiness for medical engagement in self-

care. Due to limited staff resources at the onset, HCV project goals and objectives took longer to achieve. The HCV project team also took the necessary time and effort to ensure goals and objectives did not add to existing stigma and developed approaches to encourage testing and treatment to ensure long-term social, emotional and physical health advantages.

## CONCLUSION

The Tribe recognized that individuals exhibiting risky behavior and, in particular, those who required treatment, were likely to affect the broader community. Any communicable disease is a threat to public health, and without appropriate measures to track, treat and reduce the spread of the disease, the larger community remained at risk. A comprehensive strategy on learning how to assess, respond and treat public health diseases such as HCV while building tribal capacity and the ability to manage other public health threats as described was a success for the tribal community and improved tribal and overall health, wellness and safety. The HSD experience as described provides an HCV model for other tribes or rural and underserved populations.

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## CONFLICT OF INTEREST

No conflicts of interest to report.

## AUTHOR CONTRIBUTIONS

Research concept and design: Gachupin, Harbaugh, Cupis, Lockwood, Tautolo; Acquisition of data: Gachupin, Amarillas, Lockwood; Data analysis and interpretation: Gachupin, Harbaugh, Amarillas, Cupis, Lockwood; Manuscript draft: Gachupin, Harbaugh, Lockwood, Tautolo; Administrative: Gachupin, Harbaugh, Amarillas, Cupis, Lockwood, Tautolo; Supervision: Gachupin

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