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Medical Nutrition Therapy Works, Saves Money, and Makes Money - Part 2: Maximizing Medical Nutrition Therapy Reimbursement

This is the second article in a series of articles to be published in The Provider *about medical nutrition therapy and access to nutrition services at IHS, tribal, and urban Indian health programs. Part 1 of this article appeared in the March 2007 issue of* The Provider.

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Introduction

In the first article in this series on medical nutrition therapy (MNT), we discussed the challenges to providing MNT and nutrition services in the Indian health system.[1] As the article pointed out, patients in the Indian health system have limited access to MNT services by registered dietitians. In fact, the Indian Health Service (IHS) estimates that only 15% of American Indians and Alaska Natives (AI/ANs) have access to a registered dietitian, and only one out of three AI/ANs with diabetes receive nutrition services from a registered dietitian.

MNT offers many advantages to the Indian health system, underscoring the importance of expanding access to this important service. Beyond its numerous health benefits, MNT helps our system save money, leverage resources, and obtain a source of revenue through reimbursement from Medicare, as well as Medicaid and private insurance. Put simply, MNT increasingly pays for itself.[2]

This second article in the series will describe:

- reimbursement for MNT
- The team needed to maximize reimbursement
- IHS activities related to MNT reimbursement
- Other methods for obtaining MNT reimbursement

What is Medical Nutrition Therapy (MNT)?

MNT involves the use of specific nutrition services to treat and control an illness, such as diabetes. When providing MNT, a registered dietitian follows a two-step process:

Step 1: Conduct an in-depth nutrition assessment of the client and make a nutrition diagnosis.

Step 2: Provide treatment that includes diet therapy, counseling or use of specialized nutrition supplements, and nutrition evaluation and monitoring.

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Medicare Reimbursement for Medical Nutrition Therapy

As of January 1, 2002, registered dietitians and qualified nutrition professionals are able to bill Medicare Part B directly for MNT services provided to Medicare Part B beneficiaries with diabetes, end-stage kidney disease, or kidney transplant. Details of the benefit can be found in the IHS Division of Diabetes Treatment and Prevention *Step-by-Step Guide to Medical Nutrition Therapy (MNT) Reimbursement*.[4] and on the Centers for Medicare and Medicaid Services (CMS) website.[5] Additional information can be found through the resources listed at the end of this article.

In January 2006, CMS added MNT to the list of Medicare telehealth services that are eligible for reimbursement.[6] Providing MNT via telehealth services to patients in rural and underserved areas has the potential to enhance and expand nutrition services in AI/AN communities.

What Does the Medicare Medical Nutrition Therapy Benefit Include?

The Medicare MNT benefit includes:

- 3 hours of MNT in the first calendar year (i.e., January - December)
- 2 hours of MNT in subsequent calendar years
- Additional hours of MNT performed beyond the number of hours typically covered when the treating physician determines a change in medical condition, diagnosis, or treatment plan that makes additional MNT necessary.

Billing Medicare for MNT services for qualified patients with diabetes, end-stage kidney disease, and kidney transplant provides IHS, tribal, and urban Indian health care facilities with a valuable source of revenue. As Table 1 illustrates, the number of hours that the Indian health system could bill Medicare for MNT over a 2-year period is substantial. In addition, new patients are diagnosed with diabetes and kidney disease each year, adding even more billable hours. However, as the first article in this series pointed out, the Indian health system needs to address the shortage of registered dietitians to be able to tap this potential source of income.

How Much Will Medicare Pay for MNT Services in the Indian Health System?

The type of health care facility in which the MNT services are provided determines how much Medicare will pay for the MNT services. For reimbursement purposes, Indian health care facilities fall into three categories:

- Free-standing ambulatory care clinics
- Hospital outpatient clinics or "grandfathered" clinics
- Federally Qualified Health Centers

Free-standing ambulatory care clinics bill payment for MNT services under Medicare Part B. Medicare Part B will pay 80% (including deductible and coinsurance) of the lesser of *either* the actual charge *or* 85% of the physician fee schedule payment rate. The physician schedule payment rate *varies by state*. To obtain the current IHS physician fee schedule for your state, contact the billing office at your facility.

In *hospital outpatient clinics* and what the IHS calls *"grandfathered" clinics*, claims for MNT services are billed under Medicare Part A at the IHS All-Inclusive Rate. The IHS negotiates this rate with CMS for services provided under Medicare Part A. Because the IHS renegotiates this rate each year, it is important to check the current MNT payment rate with your billing office.[6]

At Indian health ambulatory care clinics that are designated as *Federally Qualified Health Centers* (FQHC), MNT services are considered core FQHC services. Therefore, MNT services can be reimbursed under Medicare A at the FQHC All-Inclusive Rate when provided by a registered dietitian or other qualified nutrition professional.

Everyone Has a Role in Maximizing Medical Nutrition Therapy Reimbursement

Because the IHS budget for hospitals and clinics has remained static over the past few years, the Indian health system must become more creative in obtaining revenue for services that are billable to Medicare and other payers. LCDR John Rael, BBA, MBA**,** Management and Program Analyst with the IHS Division of Business Office Enhancement, notes, "New rules and regulations are continuously being established, and it is our responsibility as an organization to maximize our

Table 1. Potential MNT hours billable to Medicare over a 2-year period.

Diagnosis	Number of Medicare-eligible AI/ ANs	MNT hours reimbursed by Medicare per patient	Total number of MNT hours reimbursed by Medicare over 2 years
Diabetes	27,281*	5 hours over a 2-year period	136,405
Non-dialysis kidney disease	1,881 †	5 hours over a 2-year period	9,405

* 2004 *IHS Diabetes Care and Outcomes Audit data.*

† U.S. Renal Data System. USRDS 2006 Annual Report: Atlas of End-Stage Renal Disease in the United States. National Institutes of Health, National Institute of Diabetes and Dig estive and Kidney Diseases, 2006.

revenue from these changes. The *Step-by-Step Guide to Medical Nutrition Therapy (MNT) Reimbursement* clearly shows how a team can come together and establish an outline to capitalize on rules and changes to regulations for newly established billable visits. To address these challenges, registered dietitians, physicians, clinic administrators, and business office staff must work together as a team to maximize revenue for billable services, such as MNT. For future endeavors, we must look to this as a model to help lay the foundation for maximizing IHS billable visits."

CAPT. Kelly Acton, MD, MPH, FACP, Director of the IHS Division of Diabetes Treatment and Prevention, agrees with LCDR Rael, stating, "Teamwork among providers, administrators, and data entry and billing personnel makes a difference — not only to the health of patients, but also to a clinic's financial bottom line."[4] As described below, each team member has a role to play in maximizing MNT reimbursement.

Reimbursement Team Roles

Registered dietitians need to establish a good working relationship with billing office, data entry, and medical records staff to document MNT services properly and include all the information needed to submit claims.

Registered dietitians need to talk to the medical director and clinic administrators about MNT reimbursement, and work with them to make MNT reimbursement an integral part of the business office's tasks.

Treating physicians must provide a written referral for their patients before registered dietitians bill for MNT services.

The team needs to develop methods for tracking claims and reimbursements and reducing unpaid claims.

Benefits coordinators can design a process to identify and verify potentially eligible patients for not only Medicare, but also for other payers, such as Medicaid and private insurance companies.

In addition, registered dietitians need to market MNT services not only to providers, but also to all members of the reimbursement team to educate them about their role in obtaining MNT reimbursement, improve access to nutrition services, and ultimately increase MNT reimbursement (see below).

Tips for Marketing MNT

Tip #1: Share quick data on how MNT works.

IHS studies have shown that patients receiving MNT from a registered dietitian (RD) have better diabetes and lipid control:

- Significantly better A1C control from RD versus non-RD education
- 20% reduction in LDL and 4.6% increase in HDL
- 18% reduction in cholesterol/ HDL ratio

National research on MNT has found:

- One- to two-unit improvement in A1C (diabetes control). Every one-unit improvement in A1C translates to a 40% reduction in diabetes-related complications
- LDL decrease of 12–16%
- Blood pressure decrease of 6/ 2 mmHg

Tip #2: Share quick data on how MNT saves money.

This article discusses how MNT can make money, but don't forget how MNT can also save money:

- MNT reduces physician visits and hospital admissions for diabetes and cardiovascular disease
- MNT reduces drug costs for treating cholesterol and diabetes

Tip #3: Show how referring patients for MNT is as easy as 1, 2, 3…

Treating physicians need to follow three easy steps when referring a patient for MNT:

- Step #1 – Include the diagnosis and diagnosis code(s) for diabetes or non-dialysis kidney disease
- Step #2 – Send recent lab data and medications with the referral form
- Step #3 – Document the medical necessity for MNT in the patient's medical chart

IHS Activities Related To Medicare Reimbursement For Medical Nutrition Therapy

As described in the first article in this series, the IHS MNT Collaborative first met in 2004 to determine how to improve access to nutrition services in AI/AN communities.[1] The goal of the collaborative is to create adequate and coordinated access to competent nutrition care. The collaborative includes a multidisciplinary group of health professionals who are working to develop strategies to achieve this goal.

The members of the collaborative are each working to increase Medicare reimbursement for MNT at their local health

care facilities. They have identified several promising and successful strategies for obtaining Medicare reimbursement, such as developing the *Step-by-Step Guide to Medical Nutrition Therapy (MNT) Reimbursement* (see below), providing education and training to registered dietitians on reimbursement, leveraging existing resources, building helpful relationships, and using new technology, such as telehealth. All of this has the potential to improve access to nutrition services and thus enhance reimbursement. The following information summarizes these strategies, which you can use at your health care facility to begin or enhance your reimbursement efforts.

Step-By-Step Guide to MNT Reimbursement

The IHS Division of Diabetes Treatment and Prevention and the IHS Santa Fe Service Unit developed the *Step-by-Step Guide to Medical Nutrition Therapy (MNT) Reimbursement*, which was published in July 2006.[4] This comprehensive guide can help registered dietitians and other health professionals obtain Medicare reimbursement for MNT by providing:

- An overview of MNT Medicare reimbursement
- Details on the steps involved in obtaining MNT reimbursement
- An extensive list of resource materials
- Ready-to-use forms, including a sample physician referral form, sample MNT superbills, and tracking form and documentation templates to help you more easily and quickly submit reimbursement requests
- Information on reimbursement that applies specifically to IHS and tribal health programs

The IHS Division of Diabetes mailed this guide to registered dietitians and nutritionists at all IHS, tribal, and urban Indian health programs and provided copies to all IHS billing office coordinators. The guide is available on the IHS Division of Diabetes website at: *http://www.ihs.gov/medicalprograms/diabetes/resources/mnt_guide06_index.asp*. You can use the website to order the guide through the on-line catalogue, or you can download and print the guide directly from the website.

The IHS Division of Diabetes uses the *Step-by-Step Guide to MNT Reimbursement* as the basis for training on Medicare reimbursement for MNT for registered dietitians, nutritionists, and other interested parties. The IHS Division of Diabetes also offers technical assistance through its chief nutrition consultant, CAPT Tammy Brown MPH, RD, BC-ADM, CDE, who can also help answer questions about the guide.

Leveraging Existing Resources and Building Helpful Relationships: Sells Service Unit

When Jimmie Strock, MS, RD, Director of Nutrition and Dietetic Services, and her colleagues at the Sells Service Unit began seeking Medicare reimbursement for MNT, they set their sights on a high reimbursement rate. To achieve this goal, they developed an MNT superbill and used existing referral forms and facility reports to track claims. They also used the electronic health record (EHR) to help with timely and consistent data collection processes.

In addition to using these resources, Ms. Strock and her team proactively developed relationships to facilitate their reimbursement efforts. First, they focused on developing a good working relationship with the billing office. She notes that, "Establishing a good rapport with the billing office is essential to obtaining successful reimbursement process."

Once the billing office team was on board with plans to pursue reimbursement, Ms. Strock and the billing office personally contacted critical personnel from potential third party payers. "Most of the information discussed was exactly what was already included in the *Step-by-Step Guide to MNT Reimbursement*, but having these discussions seemed to establish a personal relationship. These interactions were essential to help us understand what we could and could not bill for and what the proper process was for doing so," says Ms. Strock.

Ms. Strock further suggests that those interested in Medicare reimbursement for MNT "Read and re-read the *Step-by-Step Guide to MNT Reimbursement*," which she affectionately refers to as the "bible" for MNT reimbursement. "Every time I read it, I would understand the steps better," she says.

The hard work of the Sells Service Unit team has paid off. They have been successful in not only billing Medicare for MNT reimbursement, but also billing private insurance companies. During the first year that the Sells Service Unit billed for MNT services, the service unit collected 62.4% of the billed amount from 517 claims. Only 19.5% of their claims were denied.

Increasing Reimbursement Through Improved Access to Nutrition Services: Phoenix Indian Medical Center

As described in the first article in this series, in 2005 the Phoenix Indian Medical Center (PIMC) began looking into ways to improve access to nutrition services. The PIMC Nutrition Services Program employed several strategies that improved access to nutrition services, including:

- Physically moving (i.e., co-locating) registered dietitians to the primary care setting
- Providing the nutrition portion of the diabetes-self-management education classes
- Offering walk-in and same-day services (increased same-day services from 5% to 55%)
- Presenting the evidence base for nutrition services to health care providers

As a result of these changes, PIMC estimates that the number of patients who received nutrition services from a registered dietitian has nearly doubled since 2003.[7]

CAPT Edith Clark, MBA, RD, CDE, Director of the

Nutrition Services Program at PIMC, stated that they have been billing Medicare and private insurance companies for MNT over the past four years. "We have increased the amounts that are billed for, and have maintained approximately a 75% collection rate. From a business point of view, this has opened up opportunities when meeting with administration to discuss workload, reimbursement dollars, and staffing patterns. It has also increased the awareness among our registered dietitians of the need to document each patient encounter accurately. We continue to work collaboratively with the medical staff to maximize reimbursement by working through the referral process. We are in the process of transitioning to the EHR, which will make the electronic referral form more readily available to the providers."

CAPT Clark credits the *Step-by-Step Guide to MNT Reimbursement* with helping PIMC achieve a high collection rate from Medicare and other payers. She states "This guide created an opportunity to work more closely with the Patient Business Office. It has helped us to all speak in the same terminology."

CAPT Clark is also helping ensure that future registered dietitians are knowledgeable about and experienced in the MNT reimbursement process. "Each of the dietetic interns from the Southwestern Dietetic Internship Consortium is required to do a presentation to the staff on various aspects of reimbursement for MNT. This will give the interns an increased awareness of the reimbursement process and the necessity to work with this process in their jobs as entry level dietitians."

Telehealth: Expanding MNT Access and Reimbursement

As mentioned previously, the CMS expanded the list of Medicare telehealth services to include individual MNT effective January 2006. LT Diane Phillips, RD, LD, CDE, at the Native American Cardiology Program in Flagstaff, Arizona, is one of the first registered dietitians in the IHS to venture into the telehealth arena. Since November 2006, LT Phillips has used telehealth services to deliver real-time MNT services through the use of video-conferencing equipment to the Crow Service Unit in Crow, Montana, and the Elko Service Unit in Elko, Nevada. This integration of technology with MNT empowers patient self-care management and facilitates continuous, uninterrupted nutrition services in rural health professional shortage areas.

Although this program is fairly new, early feedback indicates that it truly benefits patients who need MNT services. Diane Wetsit, Nursing Administrator for the Crow Service Unit, notes, "The patients really like the telenutrition services." Echoing this sentiment, Sherrie Don't Mix, Diabetes Outreach Worker for the Crow Tribal Diabetes Program, adds, "I feel that the patients are more honest with you and feel comfortable that they can share more personal information." Having successfully expanded MNT access in Crow and Elko, LT Phillips and her colleagues are currently following the *Step-by-Step Guide to MNT Reimbursement* to begin seeking reimbursement for their telehealth services.

Explore Additional Sources of Revenue for Medical Nutrition Therapy

As mentioned earlier in this article, a successful strategy for increasing revenue for MNT involves seeking reimbursement from payers other than Medicare. For example, more and more states are offering Medicaid reimbursement for MNT services. For the states that do offer Medicaid reimbursement for MNT, you will need to obtain information on the state's eligibility standards; type, amount, and length of services; and payment rates for services. The effort is well worth it because Medicaid reimbursement for MNT could be a potential growth area for your clinic's revenue. You can obtain more information on Medicaid reimbursement for MNT by:

- Accessing the *State Issues Task Force Report*, available online at the American Dietetic Association (ADA) at *www.eatright.org/ada/files/FinalReport.pdf*
- Contacting your state Medicaid director. A list of directors can be found at *www.nasmd.org/about/NASMD_Member_List.rtf*

Another source of revenue for MNT is private insurance. Although a small proportion of AI/AN patients have private insurance, most private insurance plans will match or pay even higher rates than the Medicare rate for MNT services. A survey of MNT reimbursement by insurance companies found 40% of the Standard and Poor's top 25 health insurance companies provided reimbursement. Furthermore, when reimbursement was provided, the percentage of reimbursement was substantial.[8] Information on private insurance and MNT can be located on the ADA website at *www.eatright.org/cps/rde/xchg/ada/hs.xsl/advocacy_382_ENU_HTML.htm*.

Registered dietitians and billing office personnel need to be aware of what third party payers will reimburse for MNT and be proactive in helping set policies for MNT reimbursement with these payers. The ADA website (*www.eatright.org*) is a good source for local information on reimbursement from third party payers. The association also has dietetic practice groups (e.g., weight management and diabetes care and education practice groups) that have reimbursement representatives who can help you obtain information on reimbursement for MNT from all third party payers.

Summary: Get Started Today

Seeking reimbursement for MNT has far-reaching benefits for AI/AN communities by increasing access to nutrition services and providing a source of revenue from these services. As this article described, you can follow some simple steps to get started or enhance your efforts to obtain reimbursement for MNT:

- Build a team that includes registered dietitians, other providers, data entry, medical records, and billing personnel. Work with this team to facilitate communication and develop documentation processes and tracking systems for MNT reimbursement
- Read the *Step-by-Step Guide to MNT Reimbursement* and use the tools and templates that are provided in the guide
- Meet with local or Area administrators, as well as third party payer personnel
- Promote and market your efforts and successes to increase awareness of your MNT reimbursement efforts. Provide reports to your clinic administrators and finance department to highlight the increase in revenue you are generating
- Make sure that your EHR is set up to facilitate billing for MNT reimbursement
- Continuously evaluate your MNT reimbursement efforts to understand reasons for denied claims and prevent future denied claims
- Share your results, processes, and templates with other programs to help spread best practices in maximizing MNT reimbursement

At a recent IHS MNT Collaborative meeting, Dr. Charlton Wilson encouraged the group to "Put a price tag on everything you do. Let everyone know we are delivering $X dollars in nutrition services and these services need to be paid for." Ms. Strock echoed this comment: "Bill for reimbursable services, see what gets paid and what gets denied, and build on the successes. Just DO IT!"

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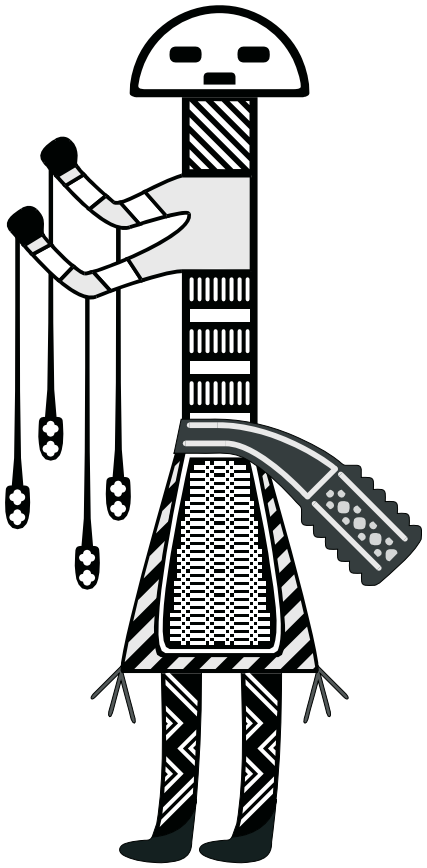

Where can I go for more Information on Medicare Reimbursement for MNT?

Contact:

Your local billing office.

Your local carrier (i.e., Trailblazer) for Medicare Part B.

IHS Division of Diabetes Treatment and Prevention:

(505) 248-4182 (ask for Tammy Brown)

tammy.brown@ihs.gov

IHS registered dietitians:

Cecelia Butler

(505) 941-9530

cecelia.butler@ihs.gov

Edith Clark

(602) 263-1532

Jimmie Strock

jimmie.strock@ihs.gov

Dianne Phillips

(928) 214-3920

dianne.phillips@ihs.gov

Other sources of information:

IHS Division of Diabetes MNT Reimbursement information
http://www.ihs.gov/MedicalPrograms/diabetes/nutrition/n_index.asp

American Dietetic Association information on MNT Reimbursement

Articles and other references for MNT
www.eatright.org/cps/rde/xchg/ada/hs.xsl/login_search_ENU_HTML.htm?dosearch=1&search=MNT+reimbursement

www.eatright.org/cps/rde/xchg/ada/hs.xsl/advocacy_382_ENU_HTML.htm

Contact your local state or affiliate American Dietetic Association (ADA) reimbursement representative.

Contact the ADA for "American Dietetic Association MNT Evidence-Based Guides for Practice: Nutrition Practice Guidelines for Type 1 and Type 2 Diabetes Mellitus" at *www.eatright.org* (Select "Shop Online", then "A to Z Index", then N).

Visit the TrailBlazer Health Enterprises, LLC, website at *www trailblazerhealth.com* and click on "Indian Health" under "Part B" for information specific to the IHS.

Improving Domestic Violence Law Enforcement Response on the Tohono O'odham Nation

Michelle S. Begay, Lieutenant, Tohono O'odham Nation Police Department, Sells, Arizona

Introduction

Domestic violence is one of the most frequently committed crimes in the United States.[1] According to the Bureau of Justice Statistics, violent crime victimization among American Indian females is more than 2.5 times that of all US females.[2] With the passage of the Violence against Women Act of 1995 (VAWA), violent crime awareness, education, and funding for domestic violence and sexual assault programs was extended to American Indian and Alaska Native tribes.[3] In the Tohono O'odham Nation Criminal Code, domestic violence is defined as a violent crime involving individuals whose relationship is one of marriage, former marriage, or cohabitation.

Law enforcement personnel are the initial responders to domestic violence and are the first opportunity for crisis intervention for victims. All other victim services stem from the initial response by law enforcement personnel, who can initiate medical, victim witness, shelter, and judicial responses. It is therefore essential that tribal communities have an effective law enforcement protocol on domestic violence as part of their coordinated community response (CCR).[4]

Background

The Tohono O'odham (TO) Nation is located in southern Arizona. It has a tribal enrollment of 25,940 and a resident population of 10,800. The land base is approximately 2.8 million acres, roughly the size of the State of Connecticut. The external reservation boundaries are located in the United States and in the State of Sonora, Mexico, including a 75-mile international border.

The TO Nation's Police Department was established in 1986. It currently has 77 law enforcement positions. The Tohono O'odham Criminal Justice Center has five judges, including the Chief Judge who oversees Civil, Criminal, Traffic, and Children's Court. Criminal cases of domestic violence can appear on the docket of judges belonging to the Tohono O'odham Judiciary. The Tohono O'odham Nation Police Department (TONPD) refers violent crime investigations to the US Attorney, who then decides which cases will be accepted for federal prosecution. Domestic violence incidents between non-Native Americans are forwarded to the County Attorney's office. If an arrest occurs, the suspect is booked into the county jail.

Table 1. Domestic violence funding sources

Source	Purpose
Tohono O'odham Natio n	Crisis intervention; Community awareness
US Department of Justice (DOJ), Office of Community Oriented Policing Services (COPS) Tribal Resources Grant Program	Police department computer equipment and four-wheel-drive vehicles to respond to remote villages
US DOJ, Office of Violence against Women, Stop Violence against Indian Women (VAIW) Grant	Community awareness programs; Domestic violence shelter; Victim advocate services
US DOJ, STOP (Services • Training • Officers • Prosecutors) Violence Against Indian Women Discretionary Grant Program	Digital cameras and voice recorders for law enforcement use in domestic violence cases; training materials; community awareness materials.
US DOJ, Bureau of Justice Assistance, Edward Byrne Justice Assistance Grant	Community policing to reduce family violence
US DOJ, Office of Justice Programs, Bureau of Justice Statistics, Tribal Criminal History Improvement Grant	Upgrade the records management system for the police department; create an integrated data system among criminal justice partners (victim witness program, prosecutor, judiciary, law enforcement, correction facilities)
US DOJ, Arrest Policy and Procedure Order Enhancement Grant Program	Implement mandatory arrest programs; training to improve tracking of domestic violence cases; training of judges; equipment and technical assistance to improve responses to domestic violence calls
US DHHS, Administration for Children and Families, Family Violence Prevention and Services Program	Provide shelter and related assistance for victims of family violence and their dependents
US DHHS, "Safe and Bright Futures" Initiative	Develop a coordinated system of prevention, intervention, treatment, and follow-through services for children who have been exposed to domestic violence
State of Arizona Criminal Justice Commission: Project Safe Neighborhoods grant	Special enforcement details to reduce family and gang violence

In 1999, the Tohono O'odham Nation created the Tohono O'odham Domestic Violence (TODV) Coalition. The coalition, consisting of community members and representatives from tribal programs, has been conducting domestic violence awareness activities in the communities. One of the challenges is extending

programs to remote areas of the reservation. The TODV Coalition's long-range goal is to develop a coordinated-community response (CCR). The TODV Coalition and the TO law enforcement have received funding from a variety of external sources, as well as from the Tohono O'odham Nation.

Permission to publish this paper was obtained from the Vice-Chairman of the Tohono O'odham, on behalf of the Nation's Executive Office.

Services to Victims

In December 2005, the Tohono O'odham Nation opened the domestic violence shelter. The shelter provides emergency housing for up to five days for domestic violence victims. There are two victim service providers serving domestic violence victims on the Tohono O'odham Nation. The Brewster Center, located 70 miles away in Tucson, Arizona, provides safety planning, a 24-hour crisis line, and shelter services. The program also provides community education, outreach and advocacy, and housing. A domestic violence advocate from the Brewster Center also holds office hours on the Tohono O'odham Nation and makes home visits.

Tohono O'odham Victim Witness Program (VWP) assists victims during the legal process. Two full-time advocates assist domestic violence victims in referrals for services, such as shelter placement, transportation, Orders of Protection, and Restraining Orders. The program also provides court accompaniment for court hearings. Through their county of residence or through federal programs, victims may also apply for financial compensation to assist them with expenses. The VWP also provides death notifications and community education on domestic violence. They assist victims in providing the court with a victim impact statement during sentencing. With only two advocates, however, the VWP cannot respond to call-outs during evenings and weekends.

The federal witness program (through the US Attorney's Office) has two victim advocates to assist victims on federal cases occurring on the Tohono O'odham Nation. The Federal Bureau of Investigation (FBI) also provides victim services through a victim witness advocate.

Police data on DV

The TO Nation's Department of Information and Technology has promoted data integration among criminal justice partners to enable better tracking of domestic violence cases and Orders of Protection. These partners include the 9-1-1 communications center in the police department, law enforcement officers' reports, adult corrections, the Office of the Prosecutor, and the Tohono O'odham Judiciary presently. The database includes all calls to 9-1-1 recorded as domestic violence cases by the Communication Dispatcher. The police officer enters the offense codes on all offenses associated with the call, including whether a firearm or knife is used. Both the communication dispatchers and police officers receive training on accurate and complete data entry. Table 2 lists items that ideally could be tracked to gain a more comprehensive picture of domestic violence cases.

Table 2. Domestic violence criminal justice data tracking

Item
DV calls received by police dispatcher
Field arrests
DV cases on Tribal judges' dockets
Referrals to U.S. Attorney
Referrals to state prosecutors
Referrals to county prosecutors
Temporary protection orders issued
Permanent protection orders issued
Disposition of cases:
Jail: length of sentence
Probation
Fines (amounts)
Cases pending
Cases dismissed
Repeat DV offenses

Law Enforcement Response Protocol

Prior to 2005, the Tohono O'odham Nation Police Department did not have a domestic violence protocol. Police officers used victim discretion on whether or not to arrest a domestic violent suspect. Repeat offenders were not prosecuted on a consistent basis; the victims of domestic violence were given the choice to prosecute.

Police supervision and adherence to police protocols are essential for improved law enforcement response. Therefore, it is necessary to have supervisory support in the implementation of any changes in police protocol. Officers have to be trained to recognize domestic violence and to enforce violations of orders of protection. Police officers must use the same procedures in all domestic violence cases. The development and adherence to police protocol is essential from all first responders, including the 9-1-1 calls answered by the communications dispatcher, to the first-line officer responding to the call for assistance for family violence, and to the supervisor who must ensure and screen the police reports that all offenses are included and the report is complete.

Policies and protocols from other agencies were reviewed as guides to develop the policy and procedure manual for the TO Police Department. These agencies included the Duluth Abuse Intervention Project, Sacred Circle, Salt River Police Department, and the Salt Lake City Police Department. The TO Nation protocol is comprehensive. It includes policies and procedures for TO police personnel involved in a domestic violence case on or off the Tohono O'odham Nation. Among the important elements of the protocol are that it requires:

- Annual training of police personnel in domestic violence issues;
- Enforcement on the Tohono O'odham Nation of orders of protection issued by any court;[5]
- Officers to provide victims with crisis intervention and shelter information;
- Completion of a responding officers' report to include all allegations of domestic violence, whether or not an arrest is

made; and documentation of injury and interviews with witnesses;
- Identification and mandatory arrest of the predominant aggressor;
- Filing of cases with the Office of the Prosecutor, whether or not a victim chooses to prosecute.

Training, Technical Assistance, and Networking

In January 2005, the police department partnered with the Center for Southwest Law and Policy (SWCLAP) to provide domestic violence training to over 30 participants from tribal programs. One TO police officer became a domestic violence instructor for the police department through a certification program offered by the Arizona Peace Officers Standards and Training Board. The officer provided training to staff in December 2005 on law enforcement police policy and police response to domestic violence. The officer was scheduled to attend a Domestic Violence Instructor Certification course with the Federal Law Enforcement Training Center in 2006.

VAWA funding was used to support various other trainings. Members of the coalition attended a one-week law enforcement training by Sacred Circle; a conference on stalking sponsored by the National Tribal Trial Justice College and the Southwest Center for Law and Policy; the bi-annual conference on victim issues in Indian country, "*Hope for all Nations: Weaving a Network of Justice, Safety, and Healing,*" sponsored by the Tribal Law and Policy Institute, University of California in Los Angeles; a community coordinated response training by Cangleska, Inc; a four-hour training on "Community Policing to Reduce Domestic Violence in Tribal communities" by the Arizona Regional Community Policing Institute; and the annual Statewide Native American Domestic Violence and Sexual Assault Networking and Awareness Conference.

The TO Nation Domestic Violence Coalition hosted a site visit by the Battered Women's Justice Project (BWJP) and the Coalition of Advocates and Attorneys Network (CAAN). Experts from Sacred Circle also conducted a site visit in February 2006. Their recommendations included developing the community coordinated response and changing the domestic violence code. The Coalition is planning to partner with the Southwest Indigenous Women's Coalition.

Community Interventions

The TO DV Coalition began community awareness activities in 1999. The murder-suicide of a young Tohono O'odham couple began the grassroots effort to address domestic violence community wide and with tribal programs. Three original members of the coalition were representatives of law enforcement, the Chief Judge of the Tohono O'odham Judiciary, and the Community Health division.

The Domestic Violence coalition initially identified three priorities: crisis intervention, shelters, and community awareness. The TO Nation opened their first domestic violence shelter in December 2005 with federal grant funding. The Tohono O'odham Nation Executive Branch provided a house; staff positions were funded through grants. There was overwhelming support from the community through the donation of household items, clothing, and a vehicle for advocates to transport victims. The Tohono O'odham Police Department assisted in the shelter planning process. An employee of the Tohono O'odham Police Department designed the shelter logo.

The opening of the shelter coincided with an assessment of the law enforcement response to domestic violence. A focus group on domestic violence was conducted with 20 community members. Among the recommendations were a need for stricter arrest policies; better transportation of victims to the shelter and other services; and more awareness among community members of the seriousness of domestic violence and of available services.

With the assistance of the Brewster Center, shelter rules and responsibilities were established. A plan was devised in which law enforcement would provide transportation of victims to a victim advocate, who would then transport the victim to the shelter. To protect victim confidentiality and safety, communications were not permitted on the law enforcement radio when a victim was to be transported to meet the advocate.

Law Enforcement and Shelter staff provided presentations to tribal communities and programs received presentations on the operations of the emergency shelter. Informational brochures about the shelter were also distributed. The location of the shelter is held confidential by staff, and law enforcement does not know the location of the shelter.

Remaining challenges

Jurisdictional issues have always posed challenges for law enforcement.[6-8] In federal cases, the FBI conducts joint investigations with the Tohono O'odham Nation Police Department. Prosecutions are handled by tribal, state, and/or federal courts depending on the race of the offender and victim. Because tribes do not have jurisdiction over non-Native American offenders, some victims are at increased risk. Cases in which the victim is a Native American and the offender is non-Native are referred to federal prosecutors. The federal process is very selective and the referral may not result in criminal charges or arrest of the suspect.

Having a mandatory arrest policy creates more case investigation involvement for law enforcement personnel. Police officers have to conduct a more in-depth investigation for domestic violence, which is more expensive and time-consuming. Therefore, through increased training and proper supervision, officers are expected to be more proactive in resolving domestic violence matters.

Each year since 1999, tribal leaders have identified domestic violence as a priority for the Tohono O'odham Nation. However, the community needs to be made aware that domestic violence is no longer tolerated. The process to change the community's perspective has been continual. The Coalition has been striving to send the message that domestic violence is a community issue, not just a law enforcement issue.

Future Activities

A future goal is to develop a family violence unit within the police department. The unit would investigate cases of domestic violence, other family offenses (such as child abuse), and sexual violence. This will also benefit first responding officers, as the unit will be trained to conduct follow up investigations and interview witnesses, including children. This unit will also work with victim advocates to ensure that victims have first-hand knowledge of their case as it moves forward in the judicial system. The unit will also assist in community awareness activities about domestic violence and sexual assault.

More complete data on domestic violence within the criminal justice system needs to be collected. There is no centralized database containing prior criminal histories of offenders. Also, information on case dispositions from the prosecuting attorney's office is not computerized. It is essential to have communication among all justice partners, and to have first hand information on case status. There are domestic violence software programs for law enforcement to assist in proper case follow-up.

With the help of technical assistance from Sacred Circle and other providers, we will continue our efforts to build a coordinated community response. Specifically, there is a need to ensure uniform treatment of victims and offenders by all service providers. The current criminal code needs to be revised to include stalking and to broaden the definition of domestic violence to include other family members and non-married intimate partners. There is also a need for continued training and networking to strengthen relationships with outside coalitions.

Conclusion

Creating change in a law enforcement organization is an enormous challenge. Support begins from the top of the organizational structure. The Tohono O'odham Nation Executive Branch, which oversees the police department, has provided tremendous support for domestic violence interventions.

There are many valuable resources for tribes seeking to improve their response to domestic violence.[9-19] Through coalition building, partnerships among and within agencies, and dedication to a community coordinated response, law enforcement can play an increasingly important role in protecting the safety, and improving the lives, of domestic violence victims.

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Injury Surveillance When There is No ER: Using RPMS to Identify Potential Injury Cases

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Introduction

The first step in reducing injuries in a community is often the establishment of a surveillance system to describe and quantify injuries.[1] Community-specific injury data are vital because there are over 500 federally-recognized tribes, each with its own culture, traditions, language, and other unique characteristics. The leading injury problems, risk factors, and protective factors in one community may be very different in another. Community-specific data allow the targeting of limited prevention resources where they are most needed.

For many years, the IHS Injury Prevention Program has promoted local data collection via the establishment of a severe injury surveillance system (SISS). An IHS protocol outlining the SISS process was introduced in the late 1980s. Step One of the SISS process is to establish a case definition. Step Two is to review a hospital's or health center's emergency room log to identify potential injury cases. In Step Three, each patient's chart is reviewed to ensure that the potential case meets the case definition. Supplemental data (e.g., specific risk factor information) may be obtained by reviewing police or fire department reports, EMS (Emergency Medical Services) run sheets, or BIA (Bureau of Indian Affairs) records of criminal investigations.

In many American Indian and Alaska Native (AI/AN) communities, developing a SISS has been challenging. First, many communities do not have local medical facilities with emergency rooms. Of the 636 facilities providing health services to AI/ANs (excluding school health centers), only 7.5% (48) are hospitals.[2] An unknown number of health centers have emergency rooms. In those communities without local emergency rooms, victims with severe injuries are seen at referral facilities whose emergency room logs are not readily accessible to IHS injury professionals. Also, many federally recognized tribes have very limited or non-existent tribal emergency response systems (EMS, police, or fire departments) to serve as a secondary source of injury information. Justifiably or not, medical record information from non-IHS facilities is often unavailable because of HIPPA (Health Insurance Portability and Accountability Act) concerns.

The Reno District IHS Office of Environmental Health and Engineering Division of Environmental Health Services (DEHS) faces many of these data challenges. Efforts to establish a SISS have been hindered by minimal coding of the cause of the injury (e.g., E-coding), lack of emergency rooms, and lack of secondary information sources. The Reno District DEHS consists of five staff who provide environmental health services to 28 tribes in Nevada, Utah, and southwestern California. The service population is approximately 30,000. Health services are provided to tribes in the district via one tribal hospital, ten tribal health centers/stations, and three IHS-managed health centers.

We sought to develop a consistent, reliable, and practical process to identify the number and types of severe injuries at each of the communities we serve. A logical foundation for such a system was the IHS RPMS (Resource and Patient Management System). RPMS is a patient management and administrative system that has been used by most IHS health care programs since the 1980s. It consists of over 60 software applications and is used at approximately 400 IHS, tribal, and urban locations nationwide.[3] The system is designed to operate on computers at both IHS and tribal healthcare facilities. The services offered (e.g., dental, laboratory, and inpatient) determine the scope of RPMS applications used by the facility.[3] For example, hospitals, which provide inpatient and outpatient care, typically run more RPMS applications than clinics that provide only outpatient care.

Methods

Reno District DEHS staff selected eight health care facilities for this project based on their use of the IHS RPMS and their willingness to participate. We defined a severe injury as a fatality; an injury that involved an amputation, loss of consciousness, or a major fracture (excluding fingers, toes, and nose); or an injury that resulted in ≤1 day of hospitalization. This definition excluded minor injuries so that attention would be focused on the most serious injuries (those that result in death, hospitalization, or severe physical consequences).

The easiest way to obtain a potential injury case list from the RPMS would be to generate a report using external cause of injury codes (E-codes). E-codes range from E800 – E999 in the ICD-9-CM manual (International Classification of Diseases – Version 9 – Clinical Modification).[4] They represent the environmental events, situation, intentionality, and other circumstances that are related to the cause of injury. Unlike diagnosis codes, E-codes are generally

not required for billing. At our participating facilities, only about 50% of injuries receive an E-code. We considered this percentage too low for generating a list of potential injury cases.

Instead, we searched RPMS using diagnosis codes (N codes) from the ICD-9-CM manual. These diagnosis codes, ranging from 800.00 to 999.9, refer to both the nature of the injury and the body part affected. Table 1 provides examples of several diagnosis and E codes.[5]

Table 1. Examples of diagnoses (N) codes and E codes, ICD-9 CM

Diagnosis code	Nature of Injury (Diagnosis)		E code[5]	E = External cause of injury
994.1	Drowning		E810-E819	Motor vehicle traffic, unintentional
824.1	Fracture of ankle--Medial malleolus, open		E968.5	Assault, motor vehicle
959.01	Head injury, unspecified		E954	Drowning, self-inflicted
806.02	Closed vertebral fracture, C1-C4 level, with anterior spinal cord syndrome		E880.0-E886.9, E888	Fall, unintentional
806.23	Closed vertebral fracture, T1-T6 level, with central cord syndrome		E957.0-.9	Fall, self-inflicted
850.0-854.1	Intracranial injury, including concussion, contusion, laceration, and hemorrhage		E919	Machinery
940-949	Burns		E908.2	Floods
943	Burns, upper limbs		E967.8	Battering and other maltreatment by non-related caregiver
940	Burns, eye		E967.3	Battering and other maltreatment by spouse or partner

Using the RPMS retrieval program called VGEN (Visit General Retrieval), visit reports were easily generated using injury diagnosis codes. Potential case lists were generated for eight different health facilities, representing four different service units for calendar years 2000 - 2003. The reports included the patient's name, chart number, date of birth, date of visit, E-code (if available), and diagnosis code. With the case list in hand, trained Environmental Health Services staff were able to review patient charts to determine whether the cases met the Reno District case definition for a severe injury. Eligible visits were also assigned a "cause of injury" (motor vehicle crash, fall, assault, etc.) by the reviewers. The data were entered into Epi Info Version 3.3.2.

A written protocol was created to ensure consistent methods of data retrieval and reporting and to serve as a guidance document for future data collectors. Field Environmental Health Services staff received five hours of on-site, chart-review training by the District staff. They were encouraged to note any questions or inconsistencies during the chart reviews. These were addressed via conference calls, or during follow-up site visits by District staff.

Results

Community-specific severe injury data are now available to eight tribes that had none before. Reno District staff shared with the tribes their individual injury profiles, including the leading causes of injury, high-risk populations by age group and gender, and injury types of greatest severity. Data reflecting four years of injury visits at one clinic are shown in Tables 2 and 3. The clinic serves a population of about 2,000 people. The clinic's injury data can help design community programs that are targeted to the leading causes of injury, serve as a baseline to monitor the impact or progress of prevention efforts, and justify proposals for additional resources to address injuries.

Table 2. RPMS, diagnosis code-based injury surveillance, Western Clinic, Reno District, CY 200-2003

Number of visits with an injury diagnosis (N) code	100
Number of visits excluded because they were repeat visits for the same injury	33
Number of charts excluded because injuries did not meet the case definition for severity	18
Number of charts excluded because of non-injury diagnoses	3
Number of severe injury cases identified	46
Number of severe injury cases with an E-code	6

Table 3. Injury profile for one Reno District (N=46)

INJURY TYPE	# CASES	ER Treated and Released	Hospitalized
Falls	22	15 (68%)	7 (32%)
Motor Vehicle	13	4 (31%)	9 (69%)
Other	7	7 (100%)	0 (0%)
Assaults	4	4 (100%)	0 (0%)
TOTAL	46	30 (65%)	16 (35%)

GENDER	
Male	27 (59%)
Female	19 (41%)

AGE GROUP	
0 – 9	8 (18%)
10 - 19	14 (31%)
20 - 39	13 (28%)
40 -59	5 (11%)
60 +	6 (12%)

Discussion

While RPMS can play a valuable role in identifying the number and types of injuries treated in health centers, it does have

limitations:

- *RPMS is not a substitute for chart review.* RPMS does not provide the depth of descriptive information found in a patient's chart. For example, alcohol intoxication as an injury-associated factor would not appear in RPMS, but might be noted in a patient's chart.
- *RPMS is only as good as the quality of the data entered.* A 1997 RPMS Surveillance Capacity Study found that understaffing, limited resources for training of data entry staff, and frequent changes in medical and support staff influenced the quality of the data.[6]
- *Although all facilities have the same software packages, there is often room for interpretation* as to what should be coded in various data entry fields. Before implementing any surveillance system, it is important to develop with the data entry staff a clear understanding of how the fields or variables are populated.
- *A health center's RPMS, for the most part, only captures information about patients who utilize that specific health center.* Many patients go "out of system" because the health center is not open all day, every day; they prefer other health providers and have third-party insurance; or they are transported by ambulance or referred for care at other sites. In general, if an injured patient is treated at another facility and no follow-up care is provided at their local health center, there would be no record of the injury in RPMS. The only exception would be if the injury was paid for in any part by Contract Health Services (CHS). Information associated with CHS obligations and expenditures must be entered into the Referred Care Information System (RCIS) within RPMS. RCIS is a group of programs created to assist with clinical and administrative management of all types of *referred care*, including care provided by Contract Health Services (CHS), non-CHS, other IHS facilities, and tribal sites. This system allows for standard sets of reports to be generated that are similar to those generated in RPMS based on visits to the health center. The Reno District is exploring the use of the RCIS as a means to identify injury hospitalizations and other severe injuries that meet the RD case definition.
- *Potential injury cases were limited to those whose diagnosis code fell within our case definition (Table 4).* This would exclude patients whose injuries (such as multiple bruises, eye injuries, or knife lacerations) could be considered severe, but whose diagnostic codes were not included in our case definition.

Conclusions

E-codes can be used in RPMS to generate a potential injury case list if the frequency of E-coding within the facility is good (e.g., > 90%)[7]. Even with high E-coding rates, however, miscoding and lack of E-code specificity can still be problems. It is therefore important to conduct a data quality assessment before launching a full-scale surveillance program. Reno District is currently working with several facilities to improve the completeness, detail, and accuracy of their E-coding. As part of this effort, we have:

- Provided training to staff with the responsibility of assigning E-Codes
- Provided training to health care providers focused on the reasons for, and importance of, E-Coding
- Encouraged health center administrative staff to review policies regarding receipt of required documentation before payment to contracted treatment facilities
- Encouraged providers to document information in the charts that would aid in assigning E-codes by answering who, what, where, and when an injury occurred
- Explored other options to get detailed information into the charts. One idea is to develop a form for the patient to fill out when checking in for their appointment. The form would become part of the medical record and be subject to all privacy regulations. This would also alleviate the burden from providers of documenting additional injury-related information.

Table 4. Diagnosis code groupings for the Reno District RPMS-based Severe Injury Surveillance System (ICD-9 CM)[4]

Clinical Diagnosis	Diagnosis code groupings
Amputation (involving upper or lower limbs)	885.0-
…of finger(s), arm/ hand	887.7
…of toes, foot, leg(s)	895.0-
	897.7
Loss of Consciousness (head injury-related)	800.00-
…fracture of skull	804.99
…concussion	850.11-
…intracranial injury	854.19
Big Bone Fractures:	
Neck and Trunk	
…vertebral column without spinal cord injury	805.00-807.4
…vertebral column with spinal cord injury	808.0-809.1
…ribs(s) and sternum	
…pelvis	
Head and Face	
…fracture of skull and face bones	800.00-804.99
Upper Limb	
…clavicle	
…scapula	810.00-
…humerus, radius &ulna	813.93
…multiple fracture involving both upper limbs and upper limbs, with upper limb with rib(s) and sternum	818.0-819.1
Lower Limb	
…femur, tibia &fibula, ankle	
…other, multiple, and ill-defined fractures of lower limb	
…multiple fracture of both lower limbs, lower with upper, and lower limb(s) with rib(s) and sternum.	820.00-824.9 827.0-829.1
Excluded Fractures:	
…carpal bones (wrist), metacarpal bones (hand), phalanges (fingers), multiple fracture of hand bones, patella, tarsal(s) and metatarsal(s); phalanges (foot)	

Despite its limitations, data collected using the RPMS-based

surveillance system has been very useful. There has been an increased interest in injury prevention because of the availability of local data. Tribes now know the frequency and types of injuries treated at their health centers, and what injuries are priorities for prevention. Tribes have already utilized the data for successful grant applications. Further efforts to improve the completeness and quality of injury data within the Reno District will include developing a protocol for retrieving potential injury cases from RCIS and exploring the value of broadening the case definition of a severe injury to include non-hospitalized injury victims who suffer severe emotional trauma (such as victims of intimate partner violence or sexual abuse), eye injuries, or multiple physical wounds.

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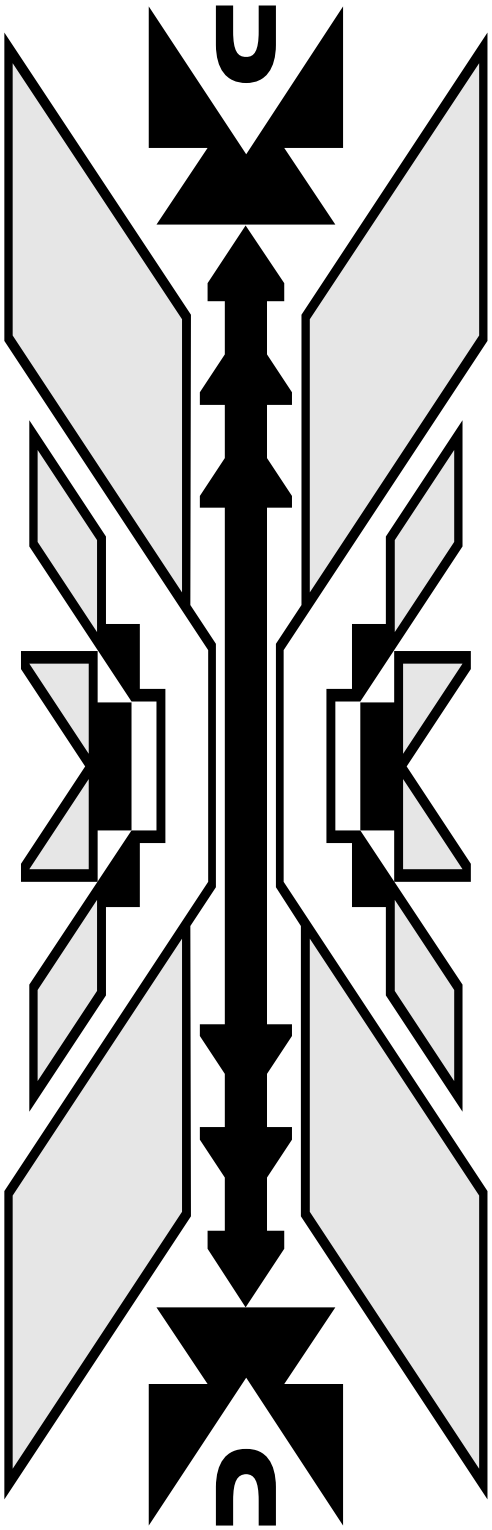

This is a page for sharing "what works" as seen in the published literature, as well as what is being done at sites that care for American Indian/Alaskan Native children. If you have any suggestions, comments, or questions, please contact Steve Holve, MD, Chief Clinical Consultant in Pediatrics at sholve@tcimc.ihs.gov.

IHS Child Health Notes

Quote of the month

"There are no answers, only stories."
Garrison Keillor

Guest Editorial

Challenges in Pediatric Rheumatic Disease: Special Issues with Native American Children

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You've probably heard this dozens of times before: "This might be an autoimmune disease. Order an ANA and a rheumatoid factor." It's a common occurrence on adult medicine wards, and all too common in pediatrics as well. It probably stems from the fact that, until recently, very few medical schools had a pediatric rheumatologist; a third of the medical schools in the United States still don't have one.[1] Thus, pediatricians have had to undertake their evaluations of children with suspected rheumatic disease or musculoskeletal complaints using models derived from adult medicine. One of the most important advances in pediatric rheumatology over the past 15 years, and the one that has received the least attention, I think, has been the growing body of research that has shown just how inappropriate those models are for the evaluation of children with musculoskeletal complaints and/or suspected rheumatic disease.

Perhaps the most surprising finding has been the documentation that isolated musculoskeletal pain is almost never the complaint with which children with arthritis present to their primary care physicians. In a retrospective study of 414 children evaluated at a university-based pediatric rheumatology clinic, McGhee and colleagues[2] demonstrated that not a single child among 76 diagnosed with juvenile rheumatoid arthritis (JRA) presented with a chief complaint of isolated musculoskeletal pain. Rather, children with JRA invariably presented with joint swelling and/or gait disturbance as their primary complaint. The gait disturbance, when present, was typically better with activity and worse with rest, exactly the opposite of what one finds in mechanical musculoskeletal pain syndromes. Here in Oklahoma, we have found that cultural considerations reinforce the absence of pain as a common presenting complaint of children with chronic arthritis. Based on these data, it is safe to make the cautious generalization that *if a child is complaining of musculoskeletal pain, chronic forms of arthritis can safely be excluded from the differential diagnosis, particularly if the child has an otherwise normal physical exam*.

There is an exception to this rule, and the exception is highly relevant to "Indian Country." Children with spondyloarthopathy (e.g., ankylosing spondylitis), a form of arthritis common in Native American boys and girls,[3] frequently present with isolated hip pain (low back pain is seldom a part of the clinical presentation of spondyloarthopathy in children). In these cases, the pain is quite typical of that found in other forms of synovitis: most prominent after periods of inactivity.

This is the point at which primary care providers like to ask, "Okay, if I consider one of these diagnoses, what tests do I order?" Unfortunately, your choices are pretty slim. For example, children with chronic polyarthritis, unlike adults, seldom express IgM-rheumatoid factor (IgM-RF) detected on conventional latex agglutination assays.[4] In 1986, Eichenfield and colleagues systematically examined the clinical utility of IgM-RF testing in children.[5] In that study, IgM-RF tests were positive in only 4.8% of 426 children tested. The test was negative in 95 children with JRA, giving it a poor negative predictive value as a screening test for arthritis. Furthermore only 5 of the 11 children who tested positive had rheumatoid arthritis, and, in each case, the positive test added no additional value in establishing the diagnosis. "Testing for rheumatoid factor is a poor screening procedure for juvenile rheumatoid arthritis in the general situations in which it is more likely to be requested…" This is a conservative statement, and it is just as reasonable, based on these data, to state categorically that *there is no reason to request a rheumatoid factor assay as a diagnostic test on any child at any time*. This sweeping statement does not take into account the higher prevalence of RF-positive disease in African American[6] and Native American[7] children and in children from the Indian subcontinent.[8] Until we have better population-specific data, this test should be generally considered one with such low positive and negative predictive values that its use should be considered suspect.

ANA tests are limited by the exact opposite problem: they are far too commonly positive in children to be diagnostically helpful in the evaluation of common musculoskeletal complaints. Malleson and colleagues[9] found that 41% of ANA tests performed at British Columbia Children's Hospital were positive at titers of 1:20 or greater. Any test that is positive in 41% of the subjects

tested will be extremely limited as a screening test for relatively rare diseases. Our group recently attempted to refine the Malleson data by trying to define settings where the results in ANA testing might be useful,[10] specifically asking whether the diagnostic utility of a positive test improved at higher titers or in specific clinical settings. We found that ANA titers of children with dermatomyositis, spondyloarthopathy, and JRA completely overlapped those of healthy children. Thus, as a screening test for chronic arthritis or inflammatory muscle disease, ANA tests have absolutely no diagnostic value. Titers of 1:1,080 and higher, however, were commonly seen in children with systemic lupus and rarely (although occasionally) seen in healthy children. Based on these data, we recommend that ANA tests be ordered as a screening test in children to answer only a single diagnostic question: *Does this child have systemic lupus?* A clinician can feel confident in telling the parent of a child 10 years of age or younger with an ANA test of < 1:160 that, "The ANA test was negative."

In the final analysis, pediatric rheumatology remains a "history and physical" subspecialty. For chronic forms of arthritis, in particular, there are simply no "tests" that tell a physician that a child has or doesn't have a given disease. Recognition of chronic forms of arthritis (and the other rheumatic diseases, for that matter) requires knowledge of the common presenting symptoms, the age of onset, and the defining clinical findings. Use of adult models to recognize pediatric diseases will only be frustrating to the physician and, more importantly, bothersome (or dangerous) to children and families. All of us start our pediatrics rotations as third year medical students being told, "Children are not just small adults." We are still learning that lesson in pediatric rheumatology.

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Infectious Disease Update
Rosalyn Singleton, MD, MPH

At the 1st International Child Health Meeting in Seattle, April 2005, several of us met to discuss the disparity in respiratory hospitalizations among American Indian and Alaska Native (AI/AN) children. We decided that minimal data were available on viral etiologies other than RSV. In October 2005 we started the Respiratory Virus Study with a grant from Medimmune.

Study of Virus Etiologies of Respiratory Hospitalizations in Alaska Native children

Background: Alaska Native infants from the Yukon Kuskokwim Delta (YKD) of Alaska have some of the highest rates of lower respiratory tract infection (LRTI) hospitalizations (284/1,000/yr) in the United States. We conducted active surveillance to describe viral and bacterial etiologies of LRTI hospitalizations in YK children.

Methods: We obtained a nasopharyngeal (NP) swab and NP wash on YKD children <3 years of age hospitalized for LRTI. We also collected NP swabs on healthy children. We performed real time polymerase chain reaction (PCR) for RSV, influenza A and B, parainfluenza virus (PIV) 1-3, human metapneumovirus (hMPV), rhinovirus, coronavirus (COV) and pertussis.

Results: From October 2005 – September 2007, we enrolled 434 hospitalized and 553 healthy children.

PCR Cases among Cases and Controls, Oct. 2005 - Sept. 2007

Viruses and Pertussis	Hospitalized Cases	Controls
RSV	102 (24%)	25 (5%)
Influenza	23 (5%)	11 (2%)
Parainfluenza	74 (17%)	23 (4%)
Metapneumovirus	66 (15%)	42 (8%)
Coronavirus	25 (6%)	29 (5%)
Rhinovirus	187 (43%)	176 (32%)
Pertussis	7 (2%)	0 (0)

*Excluding rhinovirus 41 (9%) of the positive cases were co-infected with 2 or more viruses.

Highlights

1. RSV was the most common virus, but we found an unusually high proportion of hMPV.
2. Rhinovirus occurred in nearly half of cases but was also common among controls that may have had minor cold symptoms.
3. Pertussis only occurred during a known outbreak; however, we identified 5 hospitalized children with pertussis who were not clinically recognized.
4. Peak RSV and PIV activity occurred 2 - 3 months after the US peak activity.

Study institutions: Alaska Native Tribal Health Consortium; Arctic Investigations Program-CDC; Yukon Kuskokwim Health Corporation; U of Washington; CDC/CCID Atlanta, Georgia.

Recent literature on American Indian/Alaskan Native Health

Doug Esposito, MD

Tsosie R. Cultural challenges to biotechnology: Native American genetic resources and the concept of cultural harm. *J Law Med Ethics*. 2007 Sep;35(3):396-411. *http://www.ncbi.nlm.nih.gov/sites/entrez?Db=pubmed&Cmd=ShowDetailView&TermToSearch=17714250&ordinalpos=4&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum*

This article explores the issue of rights to ownership and privacy of human tissue and the knowledge and products derived from the study of that tissue. Anglo-American legal doctrine essentially approaches the resolution of conflicts in this arena from a personal property and privacy perspective, rights that are fundamentally protected by the US Constitution. From a Western cultural standpoint, although not perfect, this doctrine seems to function reasonably well for settling conflicts arising from issues of ownership and use/misuse of information in biotechnology for members of the dominant culture. However, the author of this article suggests that "the interests of Native groups cannot be accurately understood or assessed within our legal system unless we attempt to understand the different normative conceptions of property, ownership, and privacy that exist for these groups," and that "claims made by an individual or group that are perceived to be asserting a cultural or spiritual harm based on the alleged misuse or mishandling of blood, tissue, or knowledge gained from DNA analysis may not be cognizable within existing legal theories." As a function of these and related concerns and histories, indigenous individuals and groups are legitimately suspicious of medical research and biotechnology. Deriving from the concept of "cultural rights" as applied in international human rights law, the creation of legal protection based upon "cultural harm" is offered as a possible solution to these issues for Native people.

Editorial Comment

I must admit that I have at best a rudimentary fluency in legal language and thought. As a result, I am certain that many of the points made in this article passed over my head. Nevertheless, the conceptual framework presented by the author was very useful in helping me to develop a deeper understanding of the concerns and suspicions that Native individuals and groups have with respect to biotechnology and medical research. I have been cognizant of these issues for quite some time but have never really had a complete grasp of the complexity of the concerns. For anyone desiring a better understanding of the potential dangers that biotechnological advances and medical research pose to underrepresented indigenous individuals and populations, I would certainly recommend taking a look at this article. It is well worth the difficulty of delving into the unfamiliar (and uncomfortable) realm of legalese.

Additional Reading

Pevar SL. *The Rights of Indians and Tribes: The Authoritative ACLU Guide to Indian and Tribal Rights*. 3rd Ed. 2004: New York, New York University Press. *http://www.amazon.ca/Rights-Indians-Tribes-Authoritative-Indian/dp/0814767184/ref=sr_1_3/702-4509498-9742412?ie=UTF8&s=books&qid=1191619654&sr=1-3*

Singh GK, Kogan MD. Widening socioeconomic disparities in US childhood mortality, 1969-2000. *Am J Public Health*. 2007 Sep;97(9):1658-65. *http://www.ncbi.nlm.nih.gov/sites/entrez?Db=pubmed&Cmd=ShowDetailView&TermToSearch=17666705&ordinalpos=4&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum*

Editorial Comment

The authors investigate the impact of socioeconomic disadvantage on trends in childhood mortality over a 30 year period. Although socioeconomic status (SES) is a well accepted modulator of childhood mortality, with lower standing having been shown to be inversely related to mortality in a number of studies, the authors claim that theirs is the first study linking measures of poverty to longitudinal trends in mortality. A description of the methods by which this is achieved and a repeat of all of the fascinating results and conclusions is beyond the scope of this review. I would encourage you all to check out this excellent report for yourselves. It really is timely and relevant.

On a positive note, overall mortality rates for children have been declining over the past three decades. However, the speed of this decline has not been equal for all racial/ethnic groups or socioeconomic strata within our society. As we have observed from childhood injury mortality data recently reviewed in the *IHS Child Health Notes*,[1,2] mortality rates for minorities and those standing on the lower rungs of the socioeconomic ladder

relative to white, less deprived groups are *rising* in the US. That is, disparities are increasing rather than decreasing, rendering Goal 2 of *Healthy People 2010* (the *elimination* of health disparities by the year 2010) all but an optimist's fantasy at this point. This paper goes on to suggest that this deterioration in relative mortality appears to be associated with longitudinally increasing inequity in SES within and between certain groups and regions in the US, even as the overall economy has improved. A sadder reality could not exist. As the wealthiest and most powerful nation on earth, can't we expect better?

The authors state that, "compared with children in the least deprived socioeconomic quintile, the mortality rate for children in the most deprived socioeconomic quintile was 52% higher in 1969–1971, 65% higher in 1988–1990, and 86% higher in 1998–2000." Furthermore, due to technical and methodological issues and dilutional effects of SES in the sampling units, these differences likely represent an underestimate of the true mortality, and by extension, disparity. And, this is not to mention the sizable impact that racial misclassification has on underestimating mortality rates for AI/AN minorities in studies dependent on data from the National Vital Statistics System.[1,2]

So, as time runs out on *Healthy People 2010* and ever increasing and thoughtful data emerge demonstrating persistent and widening health disparities, I cannot help but wonder, Will we redouble our efforts and target their elimination for the year 2020, or will we move on to something new?

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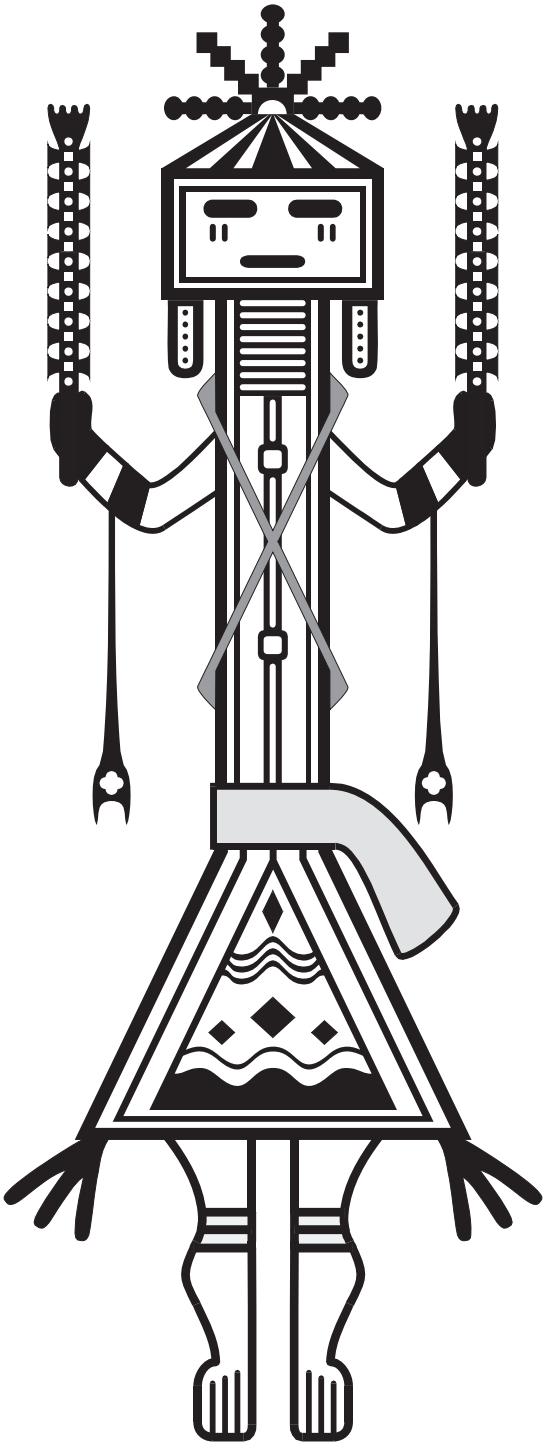

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