# **Cancer Patient Navigation Systems and Mobile Clients**

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ealth disparities among different racial, ethnic and socioeconomic groups continue to concern health professionals. Many health disparities are evident in cancer rates in the United States, with some racial and ethnic groups exhibiting disproportionate rates of incidence and deaths from different cancers. Reasons for disparities in healthcare are complex. Some of these disparities are linked to late diagnosis resulting from lower screening rates. Some patients are also being lost to follow up—times between obtaining an abnormal screening test and diagnosis, between diagnosis and start of treatment, and from treatment to resolution are longer for some groups than others. As a result, cancers in some disadvantaged groups are being diagnosed and treated at more advanced stages.

Migrant workers represent some of the most disadvantaged groups in the United States. They are part of a larger underserved population—mobile persons who travel frequently for work and other reasons. Migrant workers are predominantly Latinos, although some are African-American, Haitian, Anglo or Asian. Migrants include women, families with children, and some older men and women, though many are single men traveling without their families. Migrant workers travel far from their permanent homes. Almost half have less than a ninth grade education and many speak little or no English.

Hispanic women are less likely than non-Hispanic white women to have regular pap smears, and Hispanic men are less likely than non-Hispanic white men to have a PSA (prostate-specific antigen) test," making them more likely to be diagnosed at a later stage of cancer. Incidence of cervical cancer is almost twice as high in Hispanic women then in non-Hispanic white women." Hispanic men and women also have higher rates of cancers of the gallbladder, vagina, and penis, as well as hepatocellular carcinoma, and acute lymphocytic leukemia than their non-Hispanic white counterparts.<sup>iv</sup>

In addition to lack of insurance and inadequate access to medical care, the lack of a medical home is often identified as a significant barrier to quality care. The continuity of a relationship between clinician and patient is linked to improved preventive care and reduced hospitalization. In addition, simply locating the appropriate medical care facility in a new community is often challenging, especially if language barriers exits. Frequent moves are therefore one barrier to consistent medical care for many poor clients.

A patient navigation system is one strategy that can help cancer clients access timely and appropriate health care. By design, most patient navigation systems work within the existing local healthcare system. Patient navigators can help clients connect to healthcare systems and establish a medical home, if the client stays in that system, city or region. This raises challenges for mobile clients.

#### **Background**

The patient navigation model is attributed to Harold Freeman, MD, who instituted the use of patient navigators in 1990 at Harlem Hospital Center in New York City because he was concerned about the number of poor African American clients he saw initiating cancer treatment at late stages of the disease. His program demonstrated increases in early detection and decreases in late-stage detection at his hospital.

Freeman's Harlem model informed national legislation on patient navigation. In 2005 the US congress approved the Patient Navigator Outreach and Chronic



Disease Prevention Act, authorizing the National Cancer Institute, Health Resources and Services Administration and the Indian Health Services to award grants for model programs that provide prevention, early detection, treatment, and appropriate follow-up care services for individuals from populations with health disparities who have or are at risk for cancer and other chronic diseases. Other patient navigation systems have also been developed outside this federally funded pilot group in other settings and communities.

Patient navigation systems for cancer care are intended to provide support and guidance in accessing the cancer care system and overcoming barriers to quality,

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standard care from the time of an abnormal finding, through diagnostic tests to completion of cancer treatment.

Some of the common barriers faced by cancer patients in underserved groups include system barriers (fragmentation of care), financial barriers (lack of insurance or underinsurance), physical barriers, information and education barriers (both providerand patient-related), issues of culture and bias, and failure of providers to obtain patients' medical test or laboratory results in a timely manner

Patient navigation systems are intended to prevent the cumulative effect of these barriers—unequal delivery of cancer prevention services and delays in detection, diagnosis, and quality treatment of cancers. Their goal is to facilitate timely access to quality, standard cancer care. Some of the common qualities of patient navigator programs are:viii

· Ability to provide timely, accurate infor-

- mation in a supportive, culturally sensi-
- Knowledge of the health care delivery system that the cancer patient must depend on for care
- Knowledge of financial resources and financial alternatives available to the
- Acceptance within the health care system by administrators, physicians, and associated health care professionals and within the community as a caring, trustful health care resource

While the barriers that contribute to the disconnect between development and delivery are similar for racial and ethnic minorities, people of lower socioeconomic status, residents of rural areas and mobile underserved populations, there are no clear provisions in most patient navigation systems to address movement across county, state and country lines.

MCN Health Network services and resources are available at no charge; you may request resources, technical assistance or schedule a free training at any time by calling 512-327-2017 or visiting our website at www.migrantclinician.org/network

#### **MCN CAN-track Project**

Clinicians serving mobile populations face unique challenges to delivering appropriate health care. These include high rates of patients missing their appointments and being lost-to-follow-up. Limited availability of complete medical histories and limited access to specialty care also affect quality of care for this group. Other challenges stem from the patients' lack of health insurance, inability to purchase medications, and cultural and language differences.

In 1996, MCN and partner organizations implemented a comprehensive tracking and referral network for mobile populations dealing with tuberculosis. TBNet provides a central location where the medical records of TB patients are stored and can be accessed by the provider treating the patient. It also provides a toll free number that patients can call to get assistance in finding a source for treatment or other needed supports. Since 1996, TBNet has worked with over 1,800 participants. TBNet has assisted patients who have stayed within the United States as well as those who have moved abroad, including across the Texas/Mexico border and other countries throughout Latin America and worldwide. TBNet has shown that providing complete TB treatment to migrant patients can be successful and that it is possible to provide continuity of care to mobile populations.

Following this initiative, in 2004, MCN created CAN-track, which works with patients who have been screened or need screening for breast, cervical or colon cancer. The project was created in response to the challenges clinicians face when trying to report screening results to patients who have moved away from the area. With CAN-track, clinicians can help ensure that their patients get re-screened or receive further diagnostic tests if the screening results are abnormal. Patients can call a toll free number and receive assistance navigating the health care system when treatment is needed, as well as accessing their cancer screening and followup records from any location.

The goal of CAN-track is to increase screening rates and reduce mortality from

#### **CAN-track Case Studies**

Individual case stories of mobile clients served by CAN-track help illustrate the services provided by the program (actual names of clients are not used).

Case Study #1: Rosa: In November of 2005, the American Cancer Society requested assistance obtaining services for a woman with cervical cancer who was pregnant, did not have insurance and who was not receiving prenatal care. After her cancer diagnosis, her medical provider discontinued Depo Provera without counseling about alternatives, and Rosa became pregnant. She could not receive cancer treatment during her pregnancy. Because of her high-risk status as a cancer patient, Rosa could not receive prenatal care at the local health department or community health center, and she was having trouble finding an obstetrician who would take on a high-risk client without insurance. Rosa's family income is \$2500 per month for a family of four—too much for Medicaid and not enough to pay for insurance. CAN-track helped locate an obstetrician who would see Rosa for a set fee, and helped her find funding to pay for her prenatal care (MCN's Harvest of Hope, a local church, and an anonymous donor). CAN-track staff worked with a local social worker to arrange delivery of clothing and food to the family and enrollment into WIC. Rosa delivered a healthy baby, and CAN-track has scheduled follow-up appointments with a surgeon to evaluate the cancer.

Case Study #2: Maria,: Maria is 47 and a migrant and seasonal farmworker from Central America. She follows crop harvest seasons along the East Coast. While working picking tomatoes in autumn in Maryland, she participated in a breast cancer outreach program organized by the local health department and had a mammogram. Maria's results were inconclusive, and she needed a follow-up mammogram. The health department staff enrolled her in CAN-track. This involves filling out two forms, a consent form and a contact form. The contact form asks for the number of a relative or friend who is likely to know how to reach the patient. Maria received a plastic wallet Health Network card, and an outreach worker explained the program. Three weeks later, CAN-track staff called to see if Maria had received her results and whether she would need follow-up care. Her phone had been disconnected. They called her contact person, her daughter, and found Maria was visiting there. She had received results, but did not understand them. CANtrack staff explained the results and helped her find the community health center nearest the rural community in which her daughter lived and made an appointment for her. They also helped locate transportation services to help Maria get to the health center, and requested a copy of Maria's records sent from the Maryland hospital to the health center. Maria's name had been misspelled on the Maryland documents, so CAN-track assisted the hospital in finding the records by using other identifying data on the MCN Health Network consent form. CAN-track reported Maria's second (normal) mammogram results to the Maryland health department, which ensured that she was not lost to follow-up by that clinic.

#### **Cancer Patient Navigation Systems and Mobile Clients**

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breast, cervical, and colon cancers among migrant workers by decreasing the number of patients lost-to-follow-up. CAN-track provides a records transfer system (via fax) and care coordination services (via a tollfree telephone number) to participating clinics and service providers from the CDC National Breast and Cervical Cancer Early Detection Program (NBCCEDP). CAN-track transfers medical records throughout the United States, Mexico and Central America, integrating the services provided in those countries with the United States health care system and allowing clinicians to develop long-term care plans for their patients. The CAN-track project has three staff members. Telephone staff is selected for their bilingual abilities and cultural awareness, and are trained in the specifics of cancer care systems and potential resources for clients.

To date the project has enrolled and assisted 62 mobile clients with abnormal screening results or cancer diagnoses. Clinical staff in 27 community health centers and seven health department sites in 32 states have been trained in how to enroll clients in CAN-track. (Twelve more community health centers have signed memoranda of agreement with MCN to begin participating in the program.)

The strengths of MCN's CAN-track program thus far include the ability to transfer medical records across state and country borders. This allows the project to serve a mobile population that is national and international in scope. CAN-track staff has been able to work directly with state breast and cervical cancer programs and strengthen their abilities to serve indigent mobile clients. The primary challenge to the project to date has been getting clients enrolled in the project. Because CAN-track is not based in a clinical facility, it has limited access to clients and must rely on staff at local health departments and community health centers to make time in their already busy routines to fill out the necessary forms and explain the program to the clients.

The concept of cancer patient navigators is still relatively new. As their use increases, those concerned about the care of the poor and underserved will look on with interest to see how variations of the model work in different communities and settings, as well as for mobile clients who do not stay settled in one community. Further research is needed on how clients who work with a patient navigator do on their own if they

#### SPECIAL MESSAGE

April 1, 2007

Dear Friends:

It is our pleasure to announce a new partnership between Migrant Clinicians Network Inc. (MCN) and Farmworker Justice (FJ) to provide comprehensive, high quality capacity building assistance to Migrant Health Centers (MHC) and others that serve migrants. By combining our skills, we are better able to aid MHCs and others to strengthen and expand clinical services, provide patient education, improve farmworkers' living and working conditions, address occupational safety, and increase access to justice for migrants.

We can help your organization to address issues in a wide range of subject areas. They include clinical excellence, recruitment and retention, occupational and environmental health, health disparities, migrant demographics, emergency preparedness, workers compensation, patient navigation, and bridge case management.

Our current publications, Streamline and Farmworker Justice News, offer cutting edge information and practical solutions. In response to recent requests, we have just begun to publish Eye Opener, an electronic newsletter covering recent research and regulatory developments, available by e-mail. We also offer a wealth of helpful tools and resources on our respective websites: www.migrantclinician.org and www.fwjustice.org. A series of webcasts on clinical and health policy subjects are also available on our websites.

MCN is the oldest and largest clinical network serving the mobile underserved. For over 23 years, MCN has been working to improve the health of migrant and seasonal farmworkers and other underserved mobile populations. MCN is comprised of a professional multilingual staff, which includes physicians, nurse practitioners and public health specialists. Headquartered in Austin, TX, it has branch offices in Chico, CA, State College, PA, Salisbury, MD, Houston, TX, Lincoln, WA and El Paso, TX.

Improving the health and safety of migrant farmworkers and their families has been part of FJ's core mission since its founding in 1981. Based in Washington D.C., FJ's13-person bi-lingual staff, comprised of health professionals and attorneys, has expertise in a wide range of health and legal issues.

To access our free capacity building assistance, please contact MCN staff at (512) 327-2017 or on the web at www.migrantclinician.org or Pamela Rao at FJ (202-293-5420; www.fwjustice.org.

We look forward to working with you.

Sincerely,

Karen Mountain Chief Executive Officer Migrant Clinicians Network **Shelley Davis Deputy Director** Farmworker Justice

### Survey Results

# Increasing Cancer Survivorship in Mobile Underserved Populations

Andrea Caracostis, MD

Through funding of the Lance Armstrong Foundation, MCN conducted a survey in November, 2006 to identify the systems currently in place in migrant and community health centers affecting cancer survivorship.

This information will help MCN and others understand how to increase the capacity of clinicians to impact patient survivorship by providing critical support and quality services to cancer patients.

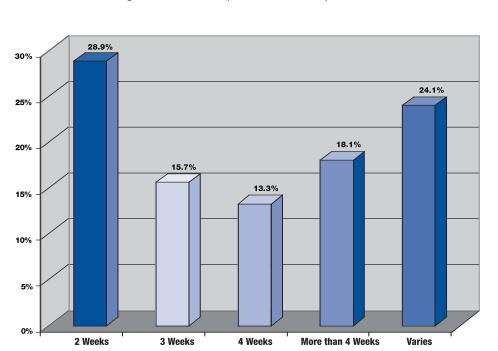


Figure 1
Time for Reporting of Abnormal Screening Results to Diagnosis

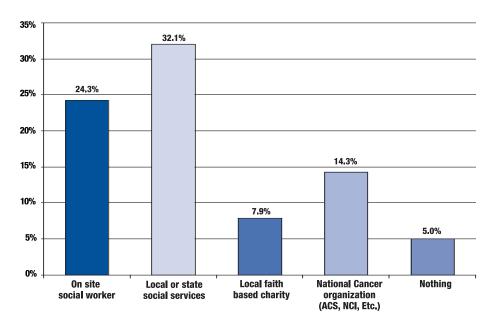


Figure 3
Most Common Follow-up Sites for Cancer Care

Little is known about how migrant and community health centers (M/CHC) screen, diagnose and follow up mobile underserved patients with cancer. This survey was designed to begin exploring these issues.

The survey was developed online through MCN's website. Notification about the survey was distributed using the National Health Disparities Collaboratives Cluster List serve and the MCN email list. Ninety nine clinicians responded to the survey and 30 of them agreed to participate in an in-depth interview via telephone.

#### **Results**

Eighty six percent of the clinics that participated in the survey said that they perform on site cancer screening.

The most common types of cancer screened for at clinics were cervical 82%, breast 80%, colon 68%, prostate 73%, testicular 55%, skin cancer 54% and 2% other cancers.

On average, 50% of adult patients in the clinics are screened for cancer.

Clinicians were asked to identify the most common reasons for not performing on-site cancer screening. The most common barriers cited were: acute care problems needing immediate attention significantly interfere with screening (49%); lack of resources to do screening (40%); patients are not interested in screening (20%) and fear among clinicians that there will be no

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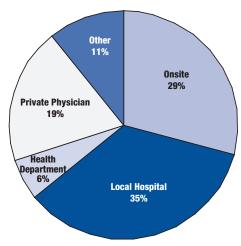


Figure 2
Where Diagnosis Occurs

Dear Friend of MCN

## Happy Mother's Day!

Looking for that special gift for a special mother? Honor your mother or a mother you love with a donation to MCN and help a migrant woman access essential healthcare during her pregnancy.

MCN is helping migrant women access timely and appropriate healthcare throughout their pregnancy. Many of these women often go without any prenatal care. Your contribution will help these women have healthier babies.

Thanks to your generous contribution, last year we helped over 30 migrant women have healthy babies. Please help us make this year a success too. Pledge your tax deductible donation by May 7, 2007 and we will send your mom or any other mom a beautiful card by U.S. mail with original artwork by one of our MCN staff members in time for Mother's Day. You may purchase your card using the form below or through our website at www.migrantclincian.org. (Direct link for e-mails). All cards will be mailed just in time for Mother's Day.

#### MCN MOTHER'S DAY PLEDGE FORM

Please fax or email the below information to the attention of Rudi Gutierrez at (512) 327-0719 or rgutierrez@migrantclinician.org

Amount of your contribution:					
	□ \$15	□ \$30	□ \$50	□ \$100	□ other amount
Name of the mother you are honoring:Address to Mail Card:					
Your Name:					
Your Address:					
Your phone number:					

Make your check out to MCN and Mail it to:

Mother's Day Campaign, Migrant Clinicians Network, P.O. Box 164285, Austin, TX 78716

If you have any questions, do not hesitate to call Rudi Gutierrez at 512.327.2017. Thanks!

#### Survey Results: Increasing Cancer Survivorship continued from page 4

access to follow-up care (16%).

For those sites that do perform onsite screen, results are delivered in an average of 2.2 weeks.

The time it takes from the reporting of abnormal results to the diagnosis varies from 2 weeks according to 29% of respondents, to more than 4 weeks according to 18% of the respondents.

Cancer diagnosis is most often performed at the local hospital (35%), followed by the clinic site (29%). Figure 2 shows the breakdown of sites where diagnosis occurs.

When providing follow-up care to cancer patients, clinics most often turn to local or

state services. Only 14% of respondents mentioned using national organizations such as NCI, ACS or LAF to provide support to their patients. Figure 3 shows where clinics turn to in order to provide follow-up care.

Conclusions

The findings of this survey are preliminary and more research should be done to explore barriers to care and how these may lead to health disparities. The barriers cited to performing on-site screening are significant and also lend themselves to further patient and provider education. In particular, the responses that indicate a lack of interest from patients and a fear among clinicians about the inability to follow up need to be addressed. It is evident that clinicians screening and following cancer patients need support encouraging their patients to get screened. Clinicians could also clearly benefit from tools to help navigate their patients through follow up and referral. MCN will continue to explore these issues in the coming months as our cancer initiative expands.

For further information or tools about cancer in migrant patients please visit our website at www.migrantclinician.org/ excellence/cancer. You may also contact Andrea Caracostis at 281-496-7522.

Editor's Note: The following article summary was taken from the current issue of the Farmworker Justice EyeOpener, a bi-monthly enewsletter. The EyeOpener covers important recent developments in research and regulation on issues affecting migrant farmworkers. This is a joint project of Farmworker Justice and the Migrant Clinicians Network supported by the Health Resources and Services Administration's Bureau of Primary Health Care. Articles will both provide a summary and advice on how this information may help heath professionals, outreach workers, promotores de salud, and advocates strengthen their care, education and advocacy on behalf of migrants and their families. This enewsletter arrives every two months and does not include online discussion. If you would like to subscribe from this list, please send a blank email to fjeyeopener-join@migrantclinician.org. You are also encouraged to send us feedback on what you used, would like to see changed or would like to see covered in future "Eye-openers." Please send feedback by email to sdavis@nclr.org or call Shelley Davis or Pamela Rao, co-authors, at 202-783-2628.

## Suggested Approaches for Studying **Linkages between Pesticide Exposure and Chronic Health Effects in Farmworkers**

McCauley LA, Anger KW, Keifer M, Langley R, Robson MG, Rohlman D. Studying Health Outcomes in Farmworker Populations Exposed to Pesticides. Environmental Health Perspectives 114(6):953-960, 2006.

any studies have shown associations between pesticide exposures and chronic health effects. Strong evidence supports the link to certain cancers, such as non-Hodgkin's lymphoma, leukemia, multiple myeloma and prostate cancer (Alavanja et al. 2004; Daniels et al. 1997); neurological problems, such as memory loss, attention deficits and cognitive dysfunction (Rohlman et al. 2001); and birth defects, especially orofacial clefts and musculoskeletal disorders (Hanke & Jurewicz 2004). Yet significant challenges remain in studying the long-term health effects of pesticide exposure in farmworkers. To advance this research, McCauley and colleagues present a brief overview of the existing literature, identify research challenges in studying farmworkers and suggest helpful approaches and methods for tackling these issues.

Using an epidemiological lens, "[t]he basic components that are necessary to effectively study the association between pesticide exposure and health effects are determination of the population at risk; a valid determination of exposure; verification of diagnosis, symptom, or biological marker of a health effect among the populations being studied; methods to link individual exposure to health effects; and the ability to establish a temporal relationship between the exposure and the health effect" (McCauley et. al. 2006 p 954). But many of these basic data are unavailable for the farmworker population (e.g., number of farmworkers, names of products and amounts of pesticides to which they are exposed, number of acute poisoning cases, complete health records for workers). Consequently, the methods and approaches for collecting data need to be customized to fit the farmworkers' needs.

One promising approach for exploring the association between exposure to neurotoxic pesticides, such as organophosphates (OPs), which are widely used in agriculture, and adverse neurological effects is to look at performance on a battery of neurobehavioral tests. Typically, this would involve a cross-sectional study design that tests exposed individuals at

one point in time and compares their performance with that of a control group of individuals with no known exposure. Exposed individuals would be matched with controls based on demographic characteristics such as age, gender, education, and cultural background or ethnicity (Anger et al. 1997). Studies using this technique have shown remarkably consistent results, across countries and exposures. When inconsistencies have occurred, they were likely due to lack of standardization in testing protocols and differences in definition of exposed individuals, among other factors.

New techniques are also being developed based on biomarkers, such as DNA damage and genotoxicity that do not depend on a stable and literate popula-

Clinicians can contribute to research on pesticide-related health outcomes by familiarizing themselves with the signs and symptoms of pesticide poisoning, making appropriate diagnoses and reporting suspected cases to state health authorities.

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#### Workers Compensation Study

## The Majority of Injured Workers in **California Have Access to Quality Care, but Minorities Report Disparities and Clinicians Believe Quality of Care Has Declined**

he vast majority of injured workers in California have access to quality medical care, according to a new study conducted by the UCLA Center for Health Policy Research for the California Division of Workers' Compensation. The report is the first comprehensive evaluation of injured workers' access to care since legislation went into effect in 2004 to reform the state's workers' compensation system.

The study also showed that the majority of injured workers are satisfied with their care, and levels of satisfaction appear unchanged from a similar study done in 1998.

Although the majority of patients —

most of whom suffered relatively minor injuries — said they were satisfied or very satisfied with their care, 22% reported that they were dissatisfied or highly dissatisfied with their treatment. In other words, 172,000 injured workers might have had bad experiences with the workers' comp insurance system in 2006.

African-American, Latino and Asian-American workers are less satisfied with the quality of care under workers compensation than white workers. African-American injured workers are more likely to have 10 or more physician visits, see more providers, report not receiving quality care, change providers due to dissatisfaction,

and report no improvement in their condition than whites, Latinos, and Asian-Americans. Latinos and Asian-Americans are also more likely to report that they did not receive quality care for their injury and had no improvement in their condition than whites.

The study also surveyed healthcare providers who said they feel that the quality of care given to injured workers had declined. According to the study, 65% of medical providers believe that care for injured workers had declined since 2004.

The full report is available at: http://www.healthpolicy.ucla.edu/pubs/ publication.asp?pubID=216#download

#### **Survey results**

A survey of workers highlighted the satisfaction of many people with healthcare but also the frustration of others.

Source: UCLA Center for Health Policy Research

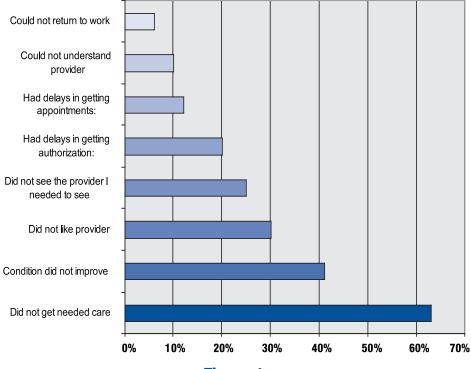


Figure 1: **Injured worker overall satisfaction in 2006** with California healthcare

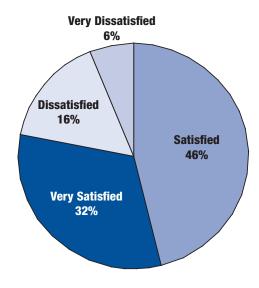


Figure 2: Injured workers' reasons for dissatisfaction with care

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leave that system and must negotiate their own care in another city or location.

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### calendar

#### **National Farmworker Health Conference**

May 9-12, 2007 Newport Beach, CA National Association of Community Health Centers (301) 347-0400 http://www.nachc.com/ela/listing.asp

#### **American Occupational Health Conference** (AOHC® 2007)

May 6-9, 2007 New Orleans, LA The American College of Occupational and Environmental Medicine (ACOEM) (847) 818-1800 http://www.acoem.org/aohc.aspx

#### The American College of **Nurse Midwives Annual Meeting & Exhibit**

May 25-31, 2007 Chicago, Illinois 240-485-1800 http://www.acnm.org/ education.cfm?id=841

## MCN

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