

streamline

The Migrant Health News Source

Cultural Humility and Compassionate Presence at the End of Life

Silvia Austerlic

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Even though illness, death, and dying are universal experiences, the ways people understand and respond to them are shaped by the attitudes and beliefs of their particular culture. Broadly speaking, our cultural background provides a road map or lens of perception through which the world is understood and interpreted. Culture impacts the meaning of health, illness, and dying; relationships between patients and health providers; how end-of-life decisions are made; communication styles; and so forth. The challenge for health care providers is to learn how cultural factors influence patients' health beliefs, behaviors, and responses to medical issues in order to assure high quality care for all.

In Western societies we tend to emphasize the technological and management issues which rob the end-of-life process its larger significance and dignity. Communicating a terminal prognosis to patients and families is much more than a medical conversation, and acknowledging the role played by culture can transform the way both providers and patients understand and relate to each other.

Cultural competence is a conceptual framework to help providers understand, appreciate, and work with individuals from diverse cultures. Its components are awareness and acceptance of cultural differences between/within cultures, self-awareness, knowledge of the patient's culture, and adaptation of skills (to better accommodate the patient's culturally-influenced needs). *Cultural competence in health care* refers to both the strategy to reduce racial/ethnic disparities in



Photo courtesy of Tia Eca

access to health services for all patient populations and the ability of the systems to provide high quality care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients' social, cultural, and linguistic needs.

I'd like to introduce another term, *cultural humility*. This phrase better reflects the complex attitude and sensitive skills required to meet the needs of patients and families in a way that empowers them to participate in a two-way therapeutic relationship, where both patient and provider are understood to have something to contribute. According to Tervalon and Murray-Garcia, cultural humility is "a commitment and active engagement in a lifelong process that individuals enter into on an ongoing basis with patients, communities, colleagues and with themselves".⁴ Cultural humility invites providers to engage in self-reflection and self-critique to bring into check the power imbalances between patients and providers. Within the scope of cultural humility providers are encouraged to use patient-focused interviewing to assess

the cultural dimensions of each patient's experience which in turn allows providers to relinquish the role of expert to the patient. Cultural humility also brings into focus the patient's potential to be a capable and full partner in the therapeutic alliance.

From my perspective as a hospice Latino community liaison I have observed the impact of culture on the concepts of illness, death, and dying in the Latino community. This has allowed me to reflect on the provider's difficult role of initiating the end-of-life (EOL) conversation and facilitating decision-making around treatment options. Since an EOL process is much more than a medical circumstance, cultural humility and a compassionate presence can have a critical impact on the patient's and family's experience; hence the need for providers to gain new understandings, knowledge, and skills.

While the demands and needs of a Latino family facing EOL issues may or may not be different from those of any other family, access

continued on page 5

Among the Most Vulnerable: Palliative and End-of-Life Care for Latino Immigrants

Tina Castañares, MD

Editor's Note: Our aim is to facilitate the use of the best available evidence for medical decision making by raising awareness of and increasing demand for information of national significance for clinicians in Migrant and Community Health Centers across the country working with Latino Immigrants.

The following piece is a summary of an article which originally appeared in the Fall, 2008, Volume 13, Number 2 issue of "Supportive Voice" a newsletter of the Supportive Care Coalition distributed to palliative care providers in the Pacific Northwest. This material developed by Dr. Castañares served as the basis for a webinar sponsored by MCN on August 22, 2012 and available through the MCN website <http://www.migrantclinician.org/webinar/resources08222012>

No data exist on utilization of hospice and palliative care services by immigrants in general, but studies suggest that only 4 percent of hospice patients nationwide are Latinos – despite their exceeding 14 percent of the U.S. population, and representing our fastest-growing ethnic or racial minority. By the year 2050, it is estimated that 29 percent of our population will be Latinos. (1) Ample evidence exists that Latinos experience significant disparities in health status and access to health care. These problems are amplified for Latinos who are also immigrants.

All of this means that “cultural competency” is a road that never ends, a path rather than a destination. The journey is an honorable and essential one for those of us offering end-of-life and palliative care, but ultimately it is also a humbling one.

To the extent that we can become knowledgeable about our society's demographic changes and what barriers are faced by Latino immigrants, we will be better equipped to reach them and provide services they need.

Most Latino immigrants in the United States are here legally – as lawful permanent residents or as “non-immigrants” with temporary visas. In individual communities, the mix varies. New growth communities such as Oregon, where large numbers of new Latino immigrants have arrived relatively recently, differ in many respects from areas in border states with long-established, often native-born Latino populations. In all cases, however, Latino ethnicity is an independent predictor of uninsurance, as is immigration status, “documented” or not.

It's crucial to remember that the broad

term “Latinos” encompasses a heterogeneous, complex set of cultures, each of them made up of differing individuals. Thus, generalizations about Latinos must be made judiciously and taken with a grain of salt, as is the case about any other racial, ethnic or cultural group.

In addition, cultures and subpopulations are always in evolution. Educational level, English proficiency, spiritual life, belief systems, literacy level and many other elements all vary within the group, and will also change within one individual over time. What a 50-year-old Catholic, Mexican-American recent immigrant to rural California believes about approaching the end of life is likely to be different in 20 years from what it is now. And her mindset will undoubtedly be very distinct from that of a 15-year-old Dominican-American boy born and raised in New York City.

In the Pacific Northwest where Dr. Castañares practices, Latinos are typically from rural interior and southern Mexico, with limited education and English. Among them, uninsurance is as high as 80-plus percent. Their elders are sometimes ineligible for Medicare. Hospice and palliative care is not covered by Emergency Medicaid for “non-qualified immigrants.” The latter term, introduced in 1996, includes not only undocumented immigrants but also those who are in the United States lawfully for fewer than five years. It also includes those on student, tourist and worker visas. (Non-qualified immigrants are also ineligible for standard federal Medicaid benefits, even when they meet all other criteria.) Nationwide, immigrants are as likely as others to enroll in health insurance when it is offered in the workplace. To summarize findings of numerous studies, almost 1 in 2 non-citizens lacks health insurance. Naturalization helps, but still doesn't even the scale. Even when naturalized citizens are included, 1 out of 3 foreign-born people are uninsured.

Family Complexities

Picture the complex, multigenerational family of Estéban and Guadalupe Lopez (not their real names), who live in a small town in Washington state. They are a middle-aged immigrant couple who have been married for 30 years; each of whom has serious chronic health problems. They have four adult children, ages 19 to 30, three of whom are married. These children were born in Mexico but

obtained lawful permanent residency many years ago; one, like their father Estéban, has already become a naturalized citizen.

Although their father speaks quite a bit of English, their mother remains monolingual in Spanish. The children are bilingual, two of them college educated. Among their spouses are two Latinos, one an unauthorized immigrant with limited English and education, and the other a native-born, college-educated U.S. citizen. The non-Latino spouse speaks only English. Estéban and Guadalupe have nine grandchildren, all of them native-born U.S. citizens, and only four of them are truly fluent in Spanish. Finally, the family brought Estéban's elderly mother, Doña Elena, from rural Mexico to live with them for the remainder of her life. She was healthy when she arrived three years ago, and her application for lawful permanent residency is in process (she is living legally in the United States).

The following case studies illustrate the challenges that might emerge if palliative or hospice care were indicated.

Doña Elena

Doña Elena comes first, as elders and children virtually always do in Latino families. She is a 75-year-old, non-literate, authorized resident of the United States who is monolingual in Spanish and in her fourth year since legal entry. Doña Elena has never been hospitalized before, and when she was last seen by a health care professional more than five years ago, she appeared well. Now she is taken to the local emergency room by her son with sudden, severe upper arm pain that has not improved over a two-day period. The ER doctor finds her to have a large right breast mass; enlarged, firm right axillary nodes; and exquisite tenderness over her left humerus.

It is not hard to guess that Doña Elena has advanced breast cancer, metastatic to bone, with a pathologic fracture. Is she eligible for Medicare or Medicaid? No, because she hasn't been here for five or more years (“non-qualified immigrant,” though legally present). She may qualify for Emergency Medicaid if she meets income criteria, but it will cover only some of her ER bills – and not cancer treatment, any outpatient follow-up, medications, home health care, long-term care or hospice.

Doña Elena is now eligible for hospice care. In remembering our caveats about overgeneralization, it is still reasonable to predict that

her family may say one or more of the following: "Please don't tell her what she has." "Please do everything you can to save her, no matter the cost." "We will take care of her ourselves." Her local hospice needs to be as prepared as possible in the realms of cultural proficiency, community partnerships and financial resources if it is to serve her and her family appropriately.

Estéban Lopez

Doña Elena's son, Estéban, has his own health problems. Estéban, 53, is a disabled former farmworker, a naturalized citizen who has spent most of the past 35 years in rural Washington. Seven years ago he was badly injured on the job; his workers' compensation case closed 19 months later. Two years ago Estéban was diagnosed with multiple sclerosis. Symptoms were mild at first, but recently his exacerbations and complications have made him mostly wheelchair-bound. He also has worsening emphysema. In the past seven months he's gone to the local ER three times, principally for shortness of breath and once because of a fall. Estéban is uninsured. He applied four months ago for Social Security disability, which might eventually provide him with Medicare coverage – but the wait for a determination may be as long as 24 months. He's not on Medicaid because his state's plan shrank, no longer covering adults without dependent children. Estéban has a primary care provider at the local community health center, and the community hospital provides some charity care coverage that has helped him in the past.

This gentleman, who could clearly benefit from interdisciplinary outpatient palliative care, is extremely worried about his mother, his own health, and his wife. He is depressed. Some of the thoughts he is likely to have are these: "I want every treatment that has any chance of making me better." "I don't want to leave my family in debt." "This is a punishment I must accept." "This is unfair, after how hard I've worked." For cultural reasons, Estéban might not complain of pain. Any one of these concerns will require artful attention by a palliative care team. In addition, Estéban may truly need interpretation and translation, but deny that he needs it – a denial that is often too readily accepted by health care professionals unable to provide service in Spanish.

Guadalupe Lopez

Finally, let us consider the case of Guadalupe, Estéban's wife. Fifty years old, in the United States for the past 20 years but undocumented, she is uninsured and uninsurable. She had always worked at least two part-time jobs, most recently in a fruit packing plant and as a child care provider, but six years ago she suddenly developed serious health problems. Guadalupe was diagnosed with autoimmune hepatitis, a quintessential "bad luck" illness;

there is nothing she could have done to prevent it, and she had no risk factors. Within a few months on her multiple lifesaving medications (including corticosteroids), she developed insulin-dependent diabetes, peptic ulcer disease and chronic anemia. More recently, her medication-induced osteoporosis and other skeletal problems have resulted in several spinal compression fractures, pelvic fractures after a mild fall, loss of her teeth, and the need for bilateral hip replacements. Pain related inactivity has led to obesity and has contributed to depression.

Guadalupe, ineligible for Medicaid or Medicare, has the same family physician as her husband, and has benefited from the hospital's patient assistance program. The health care providers who know her best note the following: her greatest fears relate to losing her care giving ability for her grandchildren, husband and mother-in-law. She often denies pain verbally, but moans as a sign of pain. She has ambivalent feelings toward medications (they have hurt her, and they have saved her life) and about the local hospital (they have helped her, but they always talk about dying and advance directives). Guadalupe does not always appear confident or permitted to speak for herself. She is thought to be using traditional Mexican remedies, and even to be receiving prescription medicines from relatives in Mexico. In fact, Guadalupe has recently become preoccupied with thoughts about her homeland and her faraway family of origin.

Guadalupe is not hospice-eligible, but like Estéban, she could certainly benefit from interdisciplinary, outpatient palliative care if it can be found in her community. In particular, skilled medical chaplaincy care might help with her spiritual and existential needs. Once again, it is not hard to imagine the cultural-proficiency, financial and linguistic resources that will be needed to provide Guadalupe with compassionate and appropriate care. No one organization or agency can do this alone. "It takes a village" – that is, strong community partnerships – in cases like hers.

We are all familiar with the concept of holding family conferences when supporting patients and caregivers. However, the multi-generational complexity of the family described above is a reminder that convening "a family conference" can be a naive oversimplification. Speaking with Estéban in English, for example, will exclude his mother and his wife, but speaking with those elders in Spanish will exclude some of the younger two generations, likely be very involved in direct care giving. Attitudes, beliefs, assimilation within the larger U.S. culture, and familiarity with our health care system vary significantly within this extended family. Knowing and accommodating these variables is part of our challenge in providing needed services.

Family Assets

Guadalupe, Doña Elena and Estéban head up a family with many medical, psychosocial and spiritual needs and challenges, and they face significant barriers to accessing needed care. But our discussion would be woefully incomplete without identifying the many assets this family has brought already to the table, and will be able to tap in future difficulties. As is well known in their community, they have strong spiritual faith and church involvement. They are well supported by fellow parishioners and by clergy. The family is a close group, mutually committed to one another. One of the adult children has worked as a CNA, and another as a medical office manager. All four of the children are avid Internet users and, with the help of the providers and educators at their community health center, have learned to identify reliable Web sites for health care information. Six grandchildren live locally and are wildly devoted to their grandparents, visiting them after school most days; as they grow older, they recognize their new role in helping with household tasks. This family, in short, will certainly benefit from more professional services, but already has vital strengths to help them do the hard work required by chronic illness, increasing disability, dying, death and grieving.

Both our individual organizations and the hospice and palliative care movement must prepare ourselves with knowledge, develop key partnerships, and advocate for compassionate, skilled care for all patients and their families – working to remove and overcome societal barriers wherever they exist among patients, providers, health care organizations, and policy makers. ■

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We at MCN agree with Dr. Castañares in her assessment that hospice and palliative care organizations provide an important resource as we transform to become migrant patient centered medical homes and to reach vulnerable populations underserved in the past. Among the essential partners in serving Latino immigrants are community and migrant health centers, churches, and existing coalitions for immigrant or Latino rights. One strategy for becoming more skillful in outreach, needs assessment and direct service – the utilization of community health workers – still new to the hospice and palliative care movement, but well-known and utilized in migrant and community health centers.

Tina Castañares

James O'Barr

[Editor's Note: Tina Castañares, MD recently retired after many years serving the migrant community. In her retirement Dr. Castañares remains very active and continues to serve in different ways. The following tribute was written by James O'Barr, a long time colleague of Dr. Castañares]

I became aware of Tina Castañares while attending my first Migrant Health Conference in San Juan, Puerto Rico, in 1990. I'm not sure we actually met or even talked, but with her dandelion head of salt-and-pepper hair and her distinctive folk-art wardrobe, Tina cut a striking figure. Nor do I remember whether I attended the workshop she co-presented on Lay Health Programs, though, as I was later to learn, she was, as usual, far ahead of the curve, in this case regarding the great value of community health workers and promotoras de salud.

While we must have crossed paths at conferences over the next few years, it wasn't until 1995 that I'm certain we actually talked, and it was because I sang. The occasion was that year's East Coast Migrant Stream Forum, held in Tarrytown, New York, and hosted by my organization, Hudson River HealthCare. I was tasked with speaking at the opening plenary about the federally-funded migrant health programs in New York. As I proudly expounded on our determination to work collaboratively, and by our collective efforts to positively affect the lives of farmworkers across the state, I suddenly stopped. "I think I can sing this better than I can speak it," I heard myself saying, whereupon I broke into an old union song my neighbor Pete Seeger had written the music for:

*Step by step the longest march
Can be won, can be won
Many stones can form an arch
Singly none, singly none
And by union what we will
Can be accomplished still
Drops of water turn a mill
Singly none, singly none*

After singing it through once, I got the audience to join in, and we did it together several times. When the plenary was over, Tina came up and expressed her complete delight. "We need to do more singing in this movement!" she said, and for many conferences after that fortuitous meeting, we did.

In the course of our conversation, we discovered that we'd both grown up in Los Angeles, had gone to the same Catholic grammar school in Hollywood, and that Tina's older brother and I had been in the



Tina Castañares

same class! But while our childhood histories and love of music provided an instant bond and kick started our friendship, lives being lived a continent apart meant that Stream Forums and National Farmworker Health Conferences were the contexts in which we initially got to know one another. For me, it was an opportunity to experience some of the remarkable range of Tina's intelligence, her great diversity of interests, her skill as a teacher, her unrelenting advocacy on behalf of the disempowered, her fearlessness in speaking truth to the powerful, her fiercely passionate commitment to serve her patients, whether they are working in the fields or living in hospice, and her unrelenting activism on behalf of a more compassionate, more just, more joyful world.

Friendship with Tina has meant being on the receiving end of a stream of gifts that ebbs and flows with the season and the moment. For many years, come the holidays, I received *Tina's Favoritos*, a CD compilation of recordings, old and new, that went out to music-loving friends and family. At any time during the year, e-mails could arrive bearing links to articles and websites and many another interesting or relevant or funny objects from cyberspace that Tina feels should be shared or acted on. Birthdays are not allowed to pass without being

marked by felicitations and presents — t-shirts promoting universal health care or Dream Act activism, music CD's, books, an admired, locally produced butter dish. Once, arriving for a visit at her home on the edge of a pear orchard near Hood River, I was quickly ushered into Tina's office and urged to give a listen to a poem that had been read on the radio that morning. It was a haunting lyric by the great Zen poet Jane Hirshfield, who I'd never heard of, but whose work has since become a treasure to me.

Tina's ability to follow her immediate concerns and interests and turn them into master classes on subjects she deems (rightly, in my view) critical to our work, is reflected in some of the presentations she's done at our conferences over the years: the aforementioned *Lay Health Programs, Their Role and Impact; Fundamentals of Pesticide Illnesses; Policy Update and Current Issues for Programs Serving Aliens; The Basics: How Migrant Health is Organized and Funded; Los Olvidados: Substance Abuse and Addiction in the Farmworker Community; Immigration and Public Benefits: Migration in Context; Who are Tomorrow's Farmworkers?* I made a point of attending Tina's workshops because I always have felt confident that the subject was important if not urgent, that I would learn a great deal that I didn't already know, and that I'd have a good time, laugh a lot, and maybe even sing.

One of those workshops, *Fast Food and Farmworkers*, which I attended at the National conference held in Indianapolis in 2002, came as the American childhood obesity and Type 2 diabetes waves were cresting, and just four months after the publication of Eric Schlosser's seminal *Fast Food Nation: The Dark Side of the All-American Meal*. "This was a typical Tina tour de force that linked the occupational and other health hazards of fast food production and consumption with, not just agricultural labor, but meat processing workers, and people in the fast food service sector and other low wage jobs. "Why this subject?" she asked. To better understand, she said, the various populations we serve in our Migrant and Community Health Centers, to better understand the occupational health risks of those who work in the fast food industry, and to better understand the health risks to our patients from consumption of fast food. For most of us, those would have been more than enough reasons to offer the presentation, but Tina added a final, and for her perhaps the most impor-

continued on page 7

to care and the quality of care are affected by cultural attitudes, practices, and concepts that are not self-evident to non-Latino caregivers. The information presented here should be considered very general in nature. Latinos are a diverse group with varied social, economic, and political reasons for being in the States. Not only do they arrive from many different countries, but they also belong to many different cultural groups. Thus, **my comments are meant to be generalizations not stereotypes.** A stereotype is an ending point; a generalization, a beginning point that can help us understand and anticipate behavior.¹

The purpose of bringing cultural differences to the foreground is not to create false dichotomy (i.e. us vs. them, good or bad, better or worse), but to acknowledge the unique cultural background of patients and families, and to foster respect and dignity in the exchange. Additionally, health providers must become knowledgeable of their patients' health care models because principles, practices, and procedures that are beneficial to one cultural group might not be beneficial, and might even be harmful, to other cultural groups. For instance, in the United States, it is customary for health providers to disclose a terminal prognosis to patients under the principle of truth-telling, respecting also the perception that the patient has the right to know the truth. However, in diverse Latino cultures, families often oppose the direct disclosure of a terminal prognosis to the patient, in the belief that they are protecting the patient from information that might be experienced as cruel, disrespectful, or giving up hope.

Regarding the relationship between patient/family and health care providers, a *personal relationship or connection* is at the heart of interactions for many Latinos. Family is considered to be the very soul of the Latino culture and plays an essential role when making health care decisions. The family has a strong influence regarding the patient's treatment and where the patient will be looked after. Family members ordinarily are very supportive and usually quite involved with care.

In general, Latinos are more likely to view health care providers as authority figures and treat them with much respect and deference. In turn, they expect a provider to be warm and friendly, to have some appreciation of the Latino culture, and to take an interest in the whole person. Central to this is the level of *confianza* or trust that makes honest communication possible. Its absence means that a patient or family member might not share important health information, such as the use of traditional medicines, or difficulty in understanding medication instruction.

For more information and resources on palliative and hospice care for Latino populations go to MCN's website, www.migrantclinician.org/webinarresources08222012

Fatalismo – the sense that what is happening is beyond one's control, and the tendency to accept hardships as the will of God and to endure a certain amount of suffering with dignity and self-sacrifice – sometimes plays a role in health care behavior.

Death and dying are topics that many Latinos may not be willing to openly discuss, especially when a loved one is seriously ill. As health deteriorates and there is a health crisis, families usually call 911 and/or rush to the emergency room or the hospital, wanting "everything done." Unfortunately, many times patients arrive too late for technology to change the course of an illness that is very advanced. At that time, it might seem obvious to doctors and nurses that death is imminent, and aggressive treatment may look more like medical futility than life-saving technology. For health providers, the line between the time to treat and the time to let go might be much clearer than for patients and families, who are now turning towards the mainstream health care system to save the patient's life.

Signing a DNR form or making the decision of withholding or withdrawing treatment is not something about which many Latino families feel comfortable. It is difficult for one single family member to be responsible for such a critical decision, and at times continuing treatment may represent "not interfering with God's will." In cases like this, it could be convenient to have a family conference or call a spiritual guide to assist the family in making a difficult decision, one aligned to their deepest beliefs and values.

Regarding comfort care, it is not uncommon that hospice (a service that is still neither well known nor well understood in the Latino community) is presented in a way that looks more like withdrawing treatment and giving up hope. The notions of *quality of life* at the end of life and *comfort care*, the patient dying peacefully at home surrounded by loved ones and with his or her pain controlled, are *not* what patients and families have in mind when they rush to the ER. And even though in some cases the patient's life cannot be saved, there is *much* that providers can do to give patients and families the best care possible, along a continuum of care from aggressive treatment to palliative care to comfort care and hospice.

At the risk of stating the obvious, it is important to say that a conversation about the end of life is much more than a medical conversation, even when the focus is on bodily condition and treatment options. At a personal level, a terminal prognosis threatens the person's whole existence. For the family members, it is often the worst nightmare. To restore death and dying to a place of dignity and holy significance, providers need not only cultural sensitivity in order to ensure that all patients and families receive the best care possible, but also human compassion, to provide support and guidance at this most difficult time. The end of life is also a time of profound suffering. Patient and family may be the protagonists, but health providers are *not separate* from the suffering. Aside from the patient-provider relationship and the pain of seeing someone we care about suffer; the dying person becomes a mirror of our own mortality. Suffering is a universal condition, and we are part of the equation. When medicine's life-saving technologies and aggressive treatments can't offer a cure, *cultural humility* and a *compassionate presence* can greatly impact the patient's and family's experience.

I'd like to end with an insight from one of my teachers, Frank Ostaseski, founder and co-director of the End-of-Life Care Practitioner program, whose mission is to provide innovative education on spirituality and dying. He writes "*In being with someone who is dying we need to be completely ourselves. Natural and ordinary. That means to bring both our strength and vulnerability to the bedside. Professional warmth doesn't heal. This is intimate work. We can't serve from a distance. We can't travel with others in territory that we haven't explored ourselves. It's not often our expertise but the exploration of our own suffering that enables us to be of real assistance. That's what allows us to touch another human being's pain with compassion instead of with fear and pity. We have to invite it all. It is an intimacy with our own inner life that enables us to form an empathetic bridge to the other person.*"³ ■

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Providing Health Quality Care to a Tuberculosis Patient on the Move

Ricardo Garay and Edward Zuroweste, MD

MCN's Health Network provides patient navigation free of charge both domestically and internationally for patients who are mobile. Health Network is an important tool for any health care provider working with patients who may move and are difficult to maintain in care. The following case illustrates how this program can work effectively for patients, health care providers, and health care sites. This particular case focuses on a health department patient with tuberculosis (TB), but it illustrates the value that the program has for all mobile patients with any critical health issues that need follow-up. Names and other details have been changed to protect patient privacy.

Luis* was referred to Health Network in January 2012 by a health department in a southeastern state. Luis was born and raised in Guatemala where he obtained a high school education. In Guatemala he married and began working on various farms. In 2008 he left for the United States so that he might be better able to support himself and his family. He has a wife and four children still residing in Guatemala. The oldest child is a 15-year-old boy, followed by 13 and 11-year-old girls, and a 9-year-old boy.

Luis initiated treatment for Pulmonary TB in September 2011. The diagnosis was based on positive results from a bronchoscopy and spinal tap performed that same month. He was diagnosed in an eastern state, but then initiated treatment and was subsequently enrolled in Health Network by a health department in a southeastern state. The enrolling health department had previous experience with Health Network because they care for a large migrant labor force.

Luis was 36 years old at the time of enrollment in Health Network. The health care provider treating his TB enrolled him because Luis had expressed interest in looking for a job out of the area. Where he would move depended on where he found a job. Although an inter-jurisdictional reporting form had been sent between the health department that initially diagnosed Luis and the health department that began treatment, the fact that Luis was likely to move frequently based on job availability made it critical that he also participate in Health Network.

How Health Network Works

There are two ways to enroll patients into Health Network:

1. Call Health Network with the patient present. An over-the-phone interview then takes place where the patient is told how his or her medical records will be transferred and how to contact Health Network whenever a move is imminent. The interview also involves gathering contact information for the patient. Having a Health Network associate interview the patient can be extremely valuable in terms of establishing rapport with the patient and letting him or her understand how the process works. Immediately after the interview is done, forms are faxed to the facility where the patient simply signs and faxes those back, along with medical records.
2. A clinic fills out the Health Network enrollment forms, downloaded and printed from the Migrant Clinicians Network (MCN) website (<http://www.migrantclinician.org/services/network/enrollment-in-health-network.html>), making sure that the patient signs the required Consent Form and provides working phone numbers and anchor contacts. It is important that sites reassure the patient that their information is kept confidential and that having numerous working phone numbers can be advantageous. Health Network will not share personal or medical information with anyone unless consent is given by the patient. Once this paperwork is filled out, it can be returned to Health Network with the medical records.

The first thing that a Health Network associate does when paperwork is received is to build a case inside MCN's patient navigation database (if the patient is interviewed, a case is built at that point). This ensures that every clinic and patient contact is properly documented. The second step involves the verification of the contact information provided by the patient. Having multiple working numbers, particularly the information for a person that acts as an "anchor" contact, increases the likelihood of having this case accepted in a timely manner (if these numbers are incorrect or out of service Health Network will contact the enrolling clinic to obtain accurate information). Based on the particular situation, the patient will be notified of the next steps.

Call 1-800-825-8205 to speak with a Health Network Associate

Luis was enrolled through a phone interview with a Health Network Associate. During the interview the patient wrote down Health Network's toll-free telephone number and the name of his Health Network Associate. The Health Network Associate was able to stress the importance of treatment adherence. Speaking to the patient directly in Spanish, rather than through interpreter facilitated the conversation. After a thorough explanation of the program Luis felt comfortable with the system and was able to provide multiple numbers in case he could not be reached through his main number. Immediately after the interview, Health Network faxed completed enrollment forms to his location. These were reviewed and signed on the spot; patient medical records were added and faxed to Health Network within minutes.

In Luis' case, in addition to positive TB test results from the bronchoscopy and spinal tap, records showed susceptibility to INH, PZA, Ethambutol, and Rifampin. X-rays taken in November 2011 showed a small cavitary lesion in the right pulmonary apex. His lungs remained hyper-extended and there were also mildly accentuated interstitial markings. The liver function panel showed elevated AST at 135 IU/L (reference range: 0-40) and 199 IU/L (reference range: 0-55) with an initial clinical impression of critical drug induced hepatitis. These later fell within normal range in subsequent testing. Luis' diagnosis was later classified as TB Meningitis, which extended his treatment timeline. He initiated treatment with:

1. INH 300mg po daily

* not his real name

tant justification: “to be better advocates for justice.” By the end, I found the workshop so stimulating, so relevant, and so full of rich and juicy information, that I insisted that Tina had to bring it to the East Coast Migrant Stream Forum. She agreed to apply, but after the workshop was accepted, she found she had an insurmountable conflict, and couldn’t travel to Savannah. Why didn’t I do it instead? Well, that was a no-brainer—the material is exceedingly complex and covers ground I’m only vaguely familiar with and am not qualified to talk about, and most important, I’m not Tina. “Nonsense,” she said, “I’ll send you my slides and plenty of supporting information, and, as for being qualified, you know and care about farmworkers and you’re interested in and care about food. The rest is commentary!” So, armed with Tina’s confidence, I agreed to do it. And she was right: with her generous, unstinting support, I was able to take her material and make it my own, and I had the time of my life doing it. Several years later, riding the elevator at yet another conference hotel, a colleague recognized me as the presenter of *Fast Food and Farmworkers* at a previous forum. “That workshop changed my relationship to food, and how I feed my family. Really, it changed my life.”

Really, that sums it up for me too. Meeting and finding friendship with Tina Castañares has changed my life, as she has

changed so many lives, directly in the case of other friends, family, colleagues, patients, agencies and organizations, and indirectly, as in the case of that workshop attended, or those whose lives have been made better, or at least not allowed to be made any the worse, by her advocacy and by her absolute commitment to a more just, more honest, more loving world. And since these memories are called up by the news that Tina is retiring, I have no doubt that whatever “retirement” means for Tina, it will mean nothing if it does include perhaps even more work for justice as well as more joy and music.

This brings us back to where my story with Tina began, with me breaking into song at an East Coast Forum. At a National conference some years later, Tina had the idea that we should take a song by the women’s a cappella group Sweet Honey in the Rock, rewrite it to make it about farmworkers, and, with another colleague she’d recruited, perform it at the evening’s gala reception and dinner. “Ella’s Song,” about Miss Ella Baker, one of the great organizers of the Civil Rights movement, was frantically reworked—probably mostly by Tina—into “Cesar’s Song.” Reading the words now, I realize how much they are Tina’s voice, and that they are as much about Tina, and, at our best, about all of us who are not just doing a

job, but engaged in the good work of making a better world. Listen:

*We who believe in justice cannot rest
We who believe in justice
cannot rest until it comes*

*Until the health of the people in the fields
is as important as the health of the banker,
the politician, and the celebrity
We who believe in justice cannot rest
We who believe in justice
cannot rest until it comes*

*They live in shanties, they live in cars,
they are homeless with no place to hide,
but we go where they are, share what we can,
and stand right by their side, because
we who believe in justice cannot rest
We who believe in justice
cannot rest until it comes.*

*No need to clutch for power,
or for fame to hide the dust,
We lend our strength to one another,
as we stand for what is just, for
we who believe in justice cannot rest
We who believe in justice
cannot rest until it comes.*

*The older I get, the better I know
the secret of my going on,
Is when the reins are in the hands of other,
who dare to run against the storm.
We who believe in justice cannot rest
We who believe in justice
cannot rest until it comes.* ■

■ **Providing Health Quality Care to a Tuberculosis Patient on the Move** continued from page 6

2. Rifampin 600mg po daily
3. PZA 1500mg po daily
4. Ethambutol 1200mg po daily
5. Vitamin B6 50mg po daily

He was subsequently switched to twice weekly instead of daily medication as follows:

1. INH 900mg po daily
2. Rifampin 600mg po daily
3. PZA 300mg po daily
4. Ethambutol 2600mg po daily
5. Vitamin B6 50mg po daily

Health Network served as a critical tool in the framework of establishing a patient

centered medical home for Luis as he moved between health departments for treatment. During the nine months of treatment, he moved four times to three different states; traveling more than 1,100 miles during the course of his treatment. Four different health departments were involved in the treatment and management of this case. Health Network served as a central hub for the storage of patient notes, medical records and movement details. Luis was contacted a total of 32 times and there were a total of 25 separate entries relating to clinic communication. With each move, records were forwarded to the local health

department to ensure a complete patient profile for every new encounter. Luis was also contacted after every move to verify that continuity of care had been established. Unreliable transportation and scheduling conflicts were both relevant obstacles during the navigation of this case; yet competent bridge case management and active patient involvement ensured a positive outcome. Luis finished treatment in May 2012. The patient was thankful that treatment was completed. Luis is now 37 years old and he remains in the United States performing migrant work wherever it is available. ■

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Female Farmworker's Perceptions of Pesticide Exposure and Pregnancy Health

Joan Flocks, Maureen Kelley, Jeannie Economos, and Linda McCauley

[Editor's Note: The following article has been excerpted with permission from: J Immigrant Minority Health, Springer, Published online: 18, November, 2011. This journal targets academic audiences, but this article is very relevant to front line providers because it reveals attitudes and knowledge about pesticide exposure which provides clinicians with new approaches to employ when talking to their patients about pesticide exposures].

Occupational pesticide exposure may be hazardous to pregnant farmworkers, yet few studies have focused on the health of female farmworkers distinct from their male counterparts or on the impact of agricultural work tasks on pregnancy outcomes. In the current community-based participatory research study, researchers conducted five focus groups with female nursery and fernery workers in Central Florida to enhance knowledge of attitudes about occupational risks and pregnancy health and to gather qualitative data to help form a survey instrument.

Methods

Participants

Nursery Worker Community

According to community-based estimates, there are 10,000–12,000 workers in the Central Florida nursery/ foliage industry. A 1990 survey of agribusiness in Florida included a sample of 142 nurseries with 3,106 workers, 42% of whom were women. Eighty-two percent of these employees worked full-time and women were as likely as men to work full-time [1]. Nursery workers are primarily Hispanic, of Mexican origin, but there are also Haitians and African-Americans. A previous study with Florida nursery worker households showed that a majority of workers (71%) were married or cohabiting and about half (50.2%) had children in the household [2]. The women who participated in the current study were reflective of these general demographics.

Most nursery workers labor inside structures constructed of non-porous heavy plastic (glass greenhouses are not as common in Florida). There are a variety of work tasks,

including planting at conveyor belts; loading pots of plants into trays; and loading and carrying trays, boxes, and bags of soil. All tasks are performed to meet time constraints and quotas and involve close contact with plants and soil, much of which has been chemically treated.

Fernery Worker Community

According to community-based estimates, there are 13,000 workers in the Central Florida fern industry. The majority of fernery workers are Hispanic. A previous study found that a majority of fernery workers surveyed (76.2%) were married or cohabiting and a majority (64.9%) had children in the household [2]. The women who participated in the current study were reflective of these general demographics.

Fern cutters work in fields under black mesh shade cloth or large shade trees. To harvest ferns, workers bend over, thrust their arms into masses of ferns, cut fronds at their base, and bundle them into bunches of 20–25 fronds. Then they carry armloads of fern bunches to trailers waiting at the edges of the field. The most experienced fern cutters can harvest up to 300 bunches of leatherleaf fern a day. Ferns can grow thigh high in the fields and fern cutters often have full bodily contact with plants, and thus with any pesticide or fertilizer residue. In the morning when the ferns are still wet with dew, some workers wear plastic aprons or tie plastic garbage bags around their waists because unprotected clothes and skin will get completely wet.

Data Collection

Participants were recruited by trained community-based researchers. The groups were held at times convenient for the workers. They were moderated and co-moderated by community-based researchers, who administered the appropriate IRB-approved informed consent forms before the groups commenced.

Results

Workers described pesticides as those substances used to kill insects, small animals (lizards, frogs), weeds, and plant diseases; to make plants grow bigger and faster; and to

make plants bloom. Some workers consider fertilizers to be pesticides.

Workers said pesticides are applied in powder or liquid form. They believe that sometimes they are applied in liquid form through the sprinkler system. Workers do not know the names of the chemicals used at their workplaces, so they identify them according to form, color, the effect they have on a plant, or the effect they have on workers (such as causing rashes or eye irritation).

Many workers were displeased with particular practices such as applications that are too close to where workers were located or early reentry into areas that have been recently treated. Others, however, maintained that their employer followed good application practices; that an owner or applicator acted responsibly and warned or kept workers out of treated areas.

Pesticide Related Health Issues

General Pesticide-Related Health Issues

The most commonly discussed pesticide-related health problem for all types of workers was dermal irritation. Workers described dermal symptoms as rashes, white spots, welts, blisters, scars, bumps, itching, sores, and fungus. The areas affected were the hands, feet, and face. Genital areas could also be affected if a worker touched that area with contaminated hands while using the bathroom.

The second most commonly discussed problem was infected or irritated eyes, caused by pesticide drift, contaminated dirt or dust, or the touching or rubbing of eyes with contaminated hands. Workers believed that over time this eye irritation leads to vision problems. One worker specifically referred to a case of pterygium, a noncancerous condition of tissue growth on the eye often associated with agricultural work. Workers also frequently discussed respiratory problems, including "allergies," with symptoms such as sneezing, coughing, nose pain, throat irritation, and breathing difficulties. Also mentioned frequently were headaches and swollen hands, and to a lesser

continued on page 9

extent, dizziness, nausea, stomachaches, and vomiting.

Finally, some workers felt pesticide exposure could cause neurological symptoms manifested by forgetfulness and a sensation that the “mind is not working right.”

Pesticide-Related Impacts on Women

When asked how pesticides specifically affect women of childbearing age, workers mentioned some of the same general pesticide-related symptoms such as headaches, dizziness, neurological effects (“shaking”), nausea, and nose and throat irritation. They also mentioned infertility and rashes in the genital area caused by working in wet conditions.

I went to a gynecologist. She asked me where I worked. I told her in the nurseries, and I also explained to her that from the time I came to this country I worked in the fields with my parents. She told me that could be the reason why I am unable to have children.

Pesticide-Related Impacts on Pregnancy and Fetal Health

Workers felt that, in addition to the general pesticide related health issues, there were a number of potential impacts on pregnancy and fetal health. For example, a fetus could be affected by the mother’s pesticide exposure because a fetus absorbs everything that the mother absorbs.

Some workers felt that pesticide exposure could cause miscarriages. Several women said they or someone they knew had experienced a miscarriage believed to be related to workplace chemical exposure. They also believed that a baby born to a woman exposed to chemicals at the workplace was at risk for birth defects and developmental disabilities. Many of the workers had children or knew of children born with these issues. Another frequently mentioned concern was that maternal pesticide exposure caused children to be born with or to develop respiratory illnesses such as asthma.

“I have nine children; five were born in Mexico. They have never visited the hospital for any kind of illness. Four were born here; I was working in the ferns with three of them. The oldest one, an 11-year-old girl, is healthy. I did not work in the fields with her. I worked all the time in the fern fields with the rest of them. None of them are well – one had asthma, one does not reason well, and the other one seems the same. I don’t think she is all right.”

Pesticide-Related Impacts on Men

Some workers described serious rashes and

infections on men’s faces and hands. Several workers strongly believed that pesticides can cause sterility in men. They also believed that pesticides could cause infections in the male genital area and that these infections could be sexually transmitted to women. Some believed that chemicals could contaminate a man’s blood and that he could genetically transmit the impact of this contamination to a fetus.

The men who want to have children have contaminated blood. If they work with chemicals, their blood is contaminated. Then, the illness is already in the child he is going to produce. It is the same problem as the women. Or the

man becomes sterile, he can’t have children.

Treatment of Pesticide-Related Symptoms

Many women responded that little or nothing is done to resolve pesticide-related health problems for a variety of reasons—employers do not want or cannot afford to send workers to a doctor and workers do not have the time or money to go to a doctor on their own. Often, a dermatological condition was treated with a cream or ointment that a worker got from their employer or that they purchased themselves.



Photo courtesy of Earl Dotter and the National Farm Medicine Center

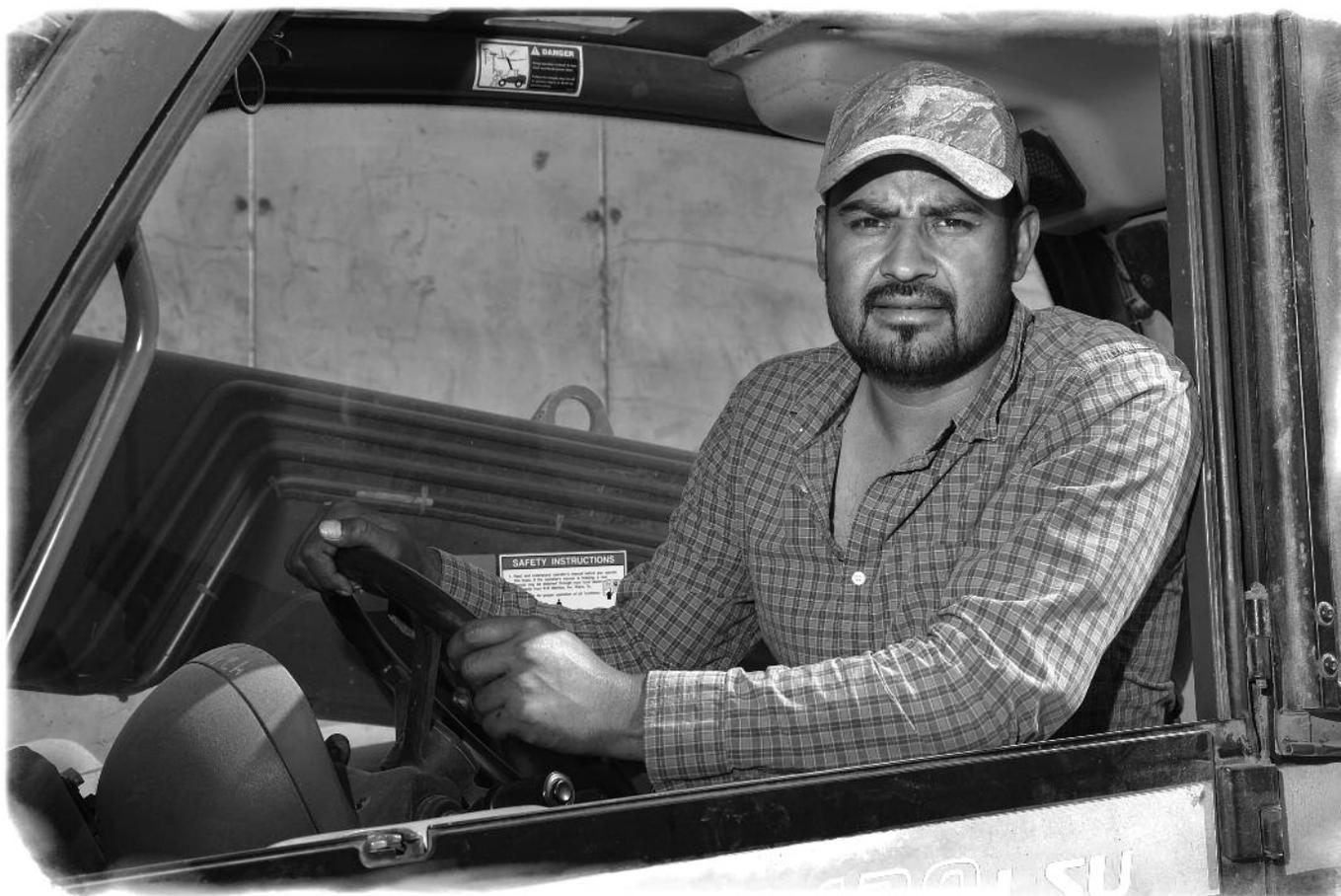


Photo courtesy of Earl Dotter and the National Farm Medicine Center

Water Quality Study Shows Need for Testing at State Migrant Camps

WINSTON-SALEM, N.C. - Sept. 13, 2012 - The drinking water at one-third of migrant farmworker camps in eastern North Carolina failed to meet state quality standards, according to a new study from Wake Forest Baptist Medical Center.

"Testing drinking water is vital to protect the public from serious diseases," said lead author Werner E. Bischoff, M.D., Ph.D., health system epidemiologist at Wake Forest Baptist. "Contaminated water puts the health of the workers who drink it at risk. It also puts the health of the surrounding community at risk because they may be drinking and bathing in water from the same sources."

The aim of the study was to assess water quality in North Carolina migrant farmworker camps and determine associations with camp housing characteristics based on N.C. Department of Labor standards.

Researchers questioned two workers in each camp about housing. They used N.C. Department of Environment & Natural Resources guidelines to collect water samples in each camp. The water samples were tested in state-certified labs to check for total

coliform bacteria and E. coli. The researchers looked at many factors for each camp that could affect water safety. These included housing conditions and distance from animal barns. They also examined whether each camp had a Certificate of Inspection from the N.C. Department of Labor, and whether the source of the camp's water was a "non-transient, non-community (NTNC) public water system."

Sixty-one of the 181 camps studied during the 2010 agricultural season failed to meet state water quality requirements. Located in 16 eastern counties, water in these camps failed the test for total coliform bacteria, meaning that the levels of bacteria in the water were high enough to cause health concerns. Two of the camps also had E. coli in the water. Coliform bacteria are indicators of contamination from human and animal waste and signal the presence of disease-causing germs in the water, said study principal investigator Thomas A. Arcury, Ph.D. Arcury is the director of the Center for Worker Health at Wake Forest Baptist which administered the study.

Safe drinking water in the camps can be achieved, he said, with stronger enforcement, more monitoring and changes to the regulations such as testing during occupancy. Arcury said that often when the water is tested before occupancy, no problems are revealed, but additional testing during occupancy would help address problems when they arise.

Water polluted by human or animal waste can cause serious health problems, including diarrhea, vomiting and dehydration, as well as hepatitis A, Legionnaires' disease and cholera, Bischoff said. "When a water system is polluted, large numbers of people can get sick." ■

Funding for the study was provided by the National Institute of Environmental Health Sciences (grant R01-ES012358).

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Female Farmworker's Perceptions of Pesticide Exposure and Pregnancy Health continued from page 9

Sometimes this remedy helped, but sometimes the cream or ointment was not the right kind or of the best quality. Sometimes dermatological conditions disappeared temporarily and then returned. A few workers mentioned alternative or home-based treatments—such as having their systems cleansed with antitoxins or soaking their affected hands in bleach or milk. Finally, some said they knew affected workers who return to Mexico for treatment because the medicine there was more effective.

Discussion

In general, studies are needed that document hazardous work conditions that some women experience during their pregnancies. This paper has focused on female farmworkers' perceptions of pesticide exposure and is part of a larger study focusing on specific workplace exposures and hazards, including biomarkers of pesticide exposure, and pregnancy outcomes among this population of workers.

The Environmental Protection Agency's Worker Protection Standard (WPS) addresses occupational pesticide exposure risks by mandating training for farmworkers and pesticide applicators to educate them about the hazards of pesticides and to reduce and mitigate exposure. The regulation requires agricultural employers to provide information about how to work more safely with pesticides and reduce exposure by washing skin and clothing at critical points during the day; information about the pesticides being used at the worksite; re-entry intervals; and access to facilities where farmworkers can wash on a regular and emergency basis.

Focus group discussion revealed that farmworker women are aware of some of the basic safety information they may have learned at pesticide trainings from their employers or other resources. When asked about ways a worker can protect herself against pesticide exposure, the focus group participants discussed many of the same protective behaviors that are recommended in the WPS. Yet they also discussed the difficulties of and barriers to implementing these measures. For example, they stated that in order to protect against pesticide exposure, all workers, especially pregnant women, should wear long pants, long-sleeved shirts, plastic gloves, a hat, a mask, long socks, boots, and sometimes safety glasses, but they recognized that even when a worker covers herself completely, she can still be exposed. Clothing gets wet with moisture from the field or with sweat and wet clothing absorbs chemicals. Plastic gloves can



tear, exposing the skin underneath. Protective equipment such as gloves and masks has to be replaced often and many employers do not provide these for their workers, thus workers have to purchase them with limited resources. Participants recommended washing or cleaning hands frequently at the workplace—including before eating, and before and after using the bathroom. However, they also reported that in many worksites there is no water for hand washing or drinking and this can exacerbate the risks for pregnant women exposed to pesticides. If there is a source of water in a workplace, workers often do not know if the water is potable. To ensure they have safe drinking water at the worksite, workers recommended bringing their own covered water bottles from home and avoiding using drinking containers that have been sitting in a work area.

Focus group participants also recognized that workers must protect other family members from exposure to pesticides carried home on their bodies and clothing. They discussed how, after work, workers should take off their shoes before entering their homes. They should not touch their children while they still have their work clothes on. They should remove their work clothes and

keep them separate from the other family clothing, wash them separately, and take a shower or bath as soon as possible after work. Yet time and resources can be a barrier to these protective behaviors.

Despite all these precautions, however, most of the focus group participants felt that the only sure way that a pregnant woman could protect herself against pesticides at the workplace is by not working there. Yet, they recognized this may not be an option for many women and so in addition to their general knowledge of protective behavior, they wanted more specific information and effective training on pesticides and pregnancy risks. They believed that this information and training could come from a number of sources, including employers, supervisors, health care providers, co-workers, or other interested parties. What seemed most important is that the information be available and accessible. ■

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calendar

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