The Problem of Invasive Cervical Cancer along the U.S.-Mexico Border:
Planning and Implementation of a Bi-national Research Project

Abstract - As states on both sides of the U.S.-Mexico border share a common history and language and have cultural and economic ties, researchers have begun to refer to this area as a single epidemiological unit. To date, however, research has tended to focus on problems that occur on one side of the border or the other. No studies identified in the literature have focused on invasive cervical cancer in the border area, despite the fact that the incidence in Mexican women and Latina women in the U.S. is high. This paper describes the planning and implementation of a cross-sectional, bi-national survey of invasive cervical cancer involving 2400 women, 15 and older, living in the Arizona-Sonora border area. To date this is the largest and most significant research project involving both academic and public sectors conducted jointly by Arizona and Sonora. WOMEN AND CANCER, 1 (5), 45-51, 1999

TC "Background"Invasive Cervical Cancer in Latinas

The incidence of invasive cervical cancer among U.S. Hispanic women is 16.2/100,000, compared with 7.5 among non-Hispanic whites. The rates among Hispanics is the second highest rate in the U.S., second only to Vietnamese women whose rate is 43/100,000 (1). In Arizona in 1995, the rate among Hispanics was 10.4 compared with 7.5 among non-Hispanic whites (1). In Mexico, invasive cervical cancer is a major cause of death (2). In 1995, the mortality rate in Mexico for cervical uterine cancer among women 25 and older was 21.5 per 100,000; in Sonora it was 22.98. Nationally, 41% of these deaths occurred among the poblation abierta, those who are the responsibility of the Secretaria de Salud Publica, while 43.2% were the responsibility of Instituto Mexicano del Seguro Social (IMSS) (4). Mortality rates during the recent period, 1990-1995, show an increase of 387.8%, from 6.99 in 1990 to over 34 in 1995, due in part certainly to better reporting (4).

Although it was known that incidence was high on both sides of the border, most cervical cancer research studies have focused on women on one side of the border or the other. Data on prevalence were not available, nor was it clear which risk factors might be responsible for putting this population at greater risk. This paper reports on the planning and implementation of a bi-national research project involving both the state of Arizona and the state of Sonora in Mexico.

The U.S.-Mexico Border Area

The U.S.-Mexico Border is a unique region of the world. Sixty five million people reside in the four U.S. and six Mexican border states, including more than 9 million who live in the 2000 miles of border towns and communities (5). The cultural and linguistic similarities are so pronounced that many believe that each side of the border has more in common with its border counterpart than with the interior of its own country. More specifically, the Arizona-Sonora border region is located in the Sonora desert and both sides share not only an ecosystem, but have unique historical roots and common cultural and economic ties. Sister city communities share economic, health and human infrastructures, as well as common issues related to growth, environmental exposure and contamination, and public health. In fact, the
border region is often referred to as a single epidemiological unit in terms of understanding the prevention and control of disease.

The border is a young, dynamic ever changing, growing bicultural society stimulated by the cultural richness of two countries. Yet little research has been done in this region to understand the specific and complex issues related to nationality and ethnicity as these factors play out within the arena of public health. While the US side of the border is characterized by serious issues related to poverty and economic development and generally considered to be a less favorable location, towns on the Mexican side of the border generally are seen as booming and fairing better, at least economically, than many towns in the interior of the country (6,7).

The US-Mexico border area faces critical issues related to health and human services. In Mexico access to health care is a guaranteed right of all citizens of Mexico under Article Four of the Constitution. For most Mexicans a complicated system of hospital networks and government agencies provides their health care, although the quality of this care is very heterogeneous. In the U.S., on the other hand, not only do the majority of border counties qualify as Health Professional Shortage Areas, but three million people, out of a population of eleven million living in the border area, are uninsured. Three out of the four states in the U.S. that have highest rates of uninsured children are located at the border. Additionally the burden of chronic diseases such as diabetes and cervical cancer, may be two to three times higher among Mexican Americans than non-Hispanic whites (8).

Background of the Bi-National Collaborative Project

In 1996, as a result of a research project examining the prevalence of multiple myeloma and lupus in Nogales, Arizona and Nogales, Sonora, the Arizona Department of Health Services (ADHS) and the Sonoran Secretaría de Salud Pública began a joint discussion to identify common public health issues in need of further research and intervention. Participants included representatives from health departments, academic institutions, and health providers from both sides of the border. Five major areas of concern were identified at that time for collaborative research and action: lead exposure, pesticide exposure, diabetes, respiratory disease, and cervical cancer.

Following that discussion, the Arizona Department of Health Services contracted directly with the University of Arizona's Rural Health Office to facilitate the development and implementation of a bi-national technical team with working groups focusing on both cervical cancer and diabetes. The Cervical Cancer team was comprised of representatives of health departments, academic institutions, and local providers from both Sonora and Arizona. The first task set by this team was to attempt to understand the context and reality of the disease in each state (Arizona and Sonora) by examining state morbidity and mortality.

The specific aim agreed upon initially by members of the team was that the study would be aimed at characterizing the factors which contribute to the disproportionately high rates of cervical cancer on both sides of the Arizona Sonora border.

As the different reporting systems used in each country made it difficult to have true comparability, the group moved in the direction of a border wide study that could establish common protocols and systems for the collection and interpretation of the data. At the same time Sonora and Arizona under a separate initiative had established a partnership to look at chlamydia at the border. As several members of this team were also involved in the cervical cancer group, the suggestion was made and accepted that the two groups be merged into one research project focusing on both issues.

The project was initiated late in 1996 and the bi-national group spent one full year meeting bimonthly. Meetings were held alternatively in each state at the border sites and in Hermosillo, Sonora and in Tucson. Meetings focused on developing the research design, protocols, instruments, etc. Data collection involving interviewing 7400 women living on both sides of the border was completed in 1998.

Research Design

Introduction. TC "Research Design": The research project had two different tracks, one of which focused on the design of the risk factor and barrier questionnaire and its implementation. This track, which is described in this paper, was comprised of social scientists and health educators. The second track focused on the clinical aspects of the study, e.g., standardizing screening exam procedures and data collection forms, and comparison and validation of cytology readings. After women had met the study criteria and the questionnaire had been filled out, clinicians were going to be asked to obtain, per clinic visit, an endocervical specimen for chlamydia, HPV test, and a Pap smear on all women undergoing a pelvic examination.

Sister city sites located along the border were selected as sites for this study. In Mexico the sites selected included the Centros de Salud (health clinics of the Secretaría de Salud Pública de Sonora) in San Luis Rio Colorado, Nogales, and Agua Prieta and Cananea. In Arizona, clinic sites included the Mariposa Community Health Center in Nogales, Valley Health Center in Somerton, Yuma County Health Department, Cochise County Health and Human Services, Bisbee, Douglas and Sierra Vista, Pima County Health Department, and Planned Parenthood clinics in Sierra Vista and Tucson. Two interior sites were selected: Tucson and Hermosillo. These sites were selected for variety of reasons related to the heterogeneous nature of the border population. Farmworkers are found in the Yuma-San Luis area. In Ambos Nogales, there are maquila and service workers. Agua Prieta/Cananea/Douglas/Bisbee/Sierra Vista have a combined population of all of the above and in addition, as each has a very small population base there was a need for several towns in this particular region. Hermosillo and Tucson were included as urban populations away from the border to see if there were
differences in the "border populations" vs. the larger urban areas away from the border. The Centros de Salud and the community health centers were chosen because we were particularly interested in the uninsured population and additionally we already had working relationships with all of these organizations.

The major goal of the study was to compare the two states and it was determined that a sample of 2400 women was needed to do this. Of the 2437 women who participated, 1400 lived in Mexico and 1037 in the U.S. Approximately 300 women were interviewed in each location.

Subjects were self-referred to clinics in Arizona and Sonora for routine care. When they checked into the clinic they were asked if they would be interested in participating in the study. If they meet the criteria for participation, the questionnaire was filled out before the exams took place. A consent form was developed according to the institutional criteria in both countries and in accordance with the study's aim. The use of this form proved to be difficult as it entailed training medical personnel in Mexico who were not familiar with this procedure. Care was given to follow up on the explanations offered to the women invited to participate in the study.

Risk Factors and Barriers Questionnaire TC "Risk Factors and Barriers Track"

Team members of this track developed two questionnaires, a short eligibility questionnaire and a 30-minute questionnaire. This team also was responsible for pilot testing the instrument, training interviewers, ensuring human subjects protection, ensuring quality control of data, and attempting to devise a system of follow-up that ensured that diagnosed women got into immediate treatment.

The eligibility questionnaire was a simple, one-page form. Women were ineligible for the study if they were pregnant, less than two months postpartum, under age 15, and not a resident of the town where the clinic was located.

To develop the risk factor and barrier questionnaire, risks were those factors that influenced whether a woman was at risk for, or had a probability of getting, a particular disease. Barriers were those factors, economic, geographic, and social/cultural, that prevent a woman from getting timely and regular screening. Barriers, thus, are likely to be predictive of a late stage at diagnosis.

Risk Factors TC "Risk Factors": In this study, risk factors were those factors that influenced whether a woman was at risk for, or had a probability of getting a particular disease. Barriers were those factors, economic, geographic, and social/cultural, that prevent a woman from getting timely and regular screening. Barriers, thus, are likely to be predictive of a late stage at diagnosis.

Factors identified in the literature as being associated with increased risk for STDs include young age (hence the need to include women 15-18 years of age), number of new partners in the last three months, total number of sexual partners, early age at first intercourse, unprotected sex, and sexual partner who has had multiple sexual partners, and women who are afraid to ask their partners to use a condom because the male will become suspicious that the woman might be having an affair (9,10). Risk factors for cervical cancer include infection with high risk type HPV, infrequent Pap smear, mother who used DES, low socio-economic status, and perhaps, diet, smoking, oral contraceptive use, and parity (for a review see 9,10).

A number of studies had identified risk factors that were particularly relevant for this study. The Health Ministry of Mexico City, using data from 12,741 gynecological cytologies and patient histories, identified as risk factors: having seven or more children, initiation of active sex life before age 14, and late menarche, after age 17(11). A second study conducted in Mexico City of 630 cases of histologically confirmed cervical cancer also found an estimated lower risk of disease related to initiating sexual relationships after age 25 (12).

Although we have literature to tell us what the risk factors are for U.S. Hispanics in general, and literature from Mexico that suggests risk factors, nothing was known about risk factors along the border. As incidence is so high in this area, it is possible that the issues faced at the border differ. Further, team members wished to develop a questionnaire that included questions on cultural practices that might affect risk of getting a disease. While monogamy of both male and female would lower risk, serial monogamy or multiple sexual partners could increase it. Further, failing to use or refusing to use condoms because of traditional beliefs could increase risk.

Barriers

Mortality and late stage at diagnosis are, according to the literature, associated with woman who have never gone for an exam; who go through long intervals (more than five years) between exams; who have an exam that gives a false negative (a focus of the clinical track); and who have a disease that grows rapidly between an exam, with a negative result, and a subsequent exam with a positive result. Higher mortality, also, is associated with women with positive results who don't receive treatment.

According to the literature women who have never had an exam or rarely have one fall into three basic categories: 1) women who lack knowledge or who have particular attitudes, beliefs and practices that are culturally influenced that prevent or inhibit screening behaviors; 2) women who frequently move within and between communities and countries; 3) and women who experience economic issues related to access to affordable services.

Cultural barriers: While at times women do not get pap smears because they do not know they are necessary, informal surveys conducted by researchers on both sides of the border indicated that this was not necessarily the case. Women were often famil-
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...iae with pelvic exams, knew what cervical cancer and STDs were, and understood the importance of pap smears and regular pelvic exams. (13) Older women might be the exception as they indicated that such exams were no longer needed after menopause (14).

Unfortunately for health care providers, knowledge that pelvic exams are important does not mean a Hispanic woman (any woman for that matter) will go in for exams. In both Mexico and the U.S., knowledge does not equal behavior and cultural barriers may play a role in keeping a woman away from a screening clinic. As one example, a woman may not go to get a screening because she is modest and would be embarrassed (15). Perhaps she, or even her husband has objections to her being examined by a male physician. Another cultural barrier is fatalism (16). This can mean that a woman may decide not to get a pap smear because she feels that illnesses are god’s will. For these women, if god decides they are to get cancer, then it is their job to accept it.

Another example of cultural beliefs and practices that can erect other barriers is the extended practice of Latino women taking care of others and living for others, and not giving sufficient attention to their own health. This is closely associated with profound cultural practices surrounding maternity and motherhood. Research in Sonora has demonstrated that women are more likely to seek medical care for their children than they are themselves (17).

Cultural barriers in the U.S., but generally not in Mexico, also include things that influence a woman’s comfort in the health care setting. Perhaps clinic staff did not speak Spanish and the woman was a monolingual Spanish speaker. Perhaps clinic staff, the front-line workers, treated her disrespectfully. Perhaps she did not feel comfortable with a male physician or there was no cultural match between provider and client.

Geographic Barriers: Geographic barriers can affect stage at diagnosis because a Mexican woman living in the U.S. may be afraid of going to a clinic in the U.S. where she fears that they may ask questions about her residency status. Geographic barriers occur when a woman has recently arrived in an area and does not know where to find a provider. Another geographic barrier occurs when a woman works in a rural area and has no transportation to a distant clinic.

Systems or Access Barriers: The systems or access barriers were serious ones as there are significant differences in the health systems found the US and in Mexico. In Mexico, access to health care is a constitutional right. Access to health care in Arizona, however, is a serious problem for the poor. There are a limited number of providers, the majority of the U.S. border counties have been designated Health Professional Shortage Areas. In addition to not being able to find a local provider, poverty and being uninsured limit access.

Undocumented women either travel to Mexico for exams or, more likely avoid getting them. Women seeking residency sta-
tus, are fearful of leaving the U.S., even though they have access to care in Mexico, but no access to medical care in the U.S.

Fear may prevent some women from seeking screening exams because of fear. Fear may stem from the fact that a woman knows that she cannot afford treatment if the screening exam reveals a problem. As women along the border expressed this to team members, they feel they are better off not knowing they have a disease, as they will just have to ignore it once it is diagnosed.

We compiled all these risk factors and barriers into a 20 minute questionnaire that also included sociodemographic questions. In developing the format, we assumed that women would be hesitant to talk with an interviewer about their sexual history. Thus we felt that our questionnaire should be self-administered. We knew that the problem with self-administered questionnaires, is that they would be difficult for the low literacy women. We worded the questions accordingly.

When we pilot tested the questionnaire we found that, regardless of site, the self-applied questionnaire, despite our attempts to keep the reading level low, was too difficult for women with a secondary, or lower educational level. We also found that many of the questions, particularly those related to birth control use and health history were complex and required probing. Surprisingly, we found that the sensitive questions related to sexual behavior were answered in greater depth in an interview situation than in the self-administered questionnaires.

At this point, we realized it was necessary to use an interview format. Thus, we now had to confront the fact that while we could assure a woman being interviewed that we would treat her information with confidentiality, we could no longer guarantee anonymity. An advantage of the interview format, however, was that it gave us the opportunity to provide a more comprehensive explanation regarding the need for confidential, but not anonymous information.

Income information also was an issue as it has been in all the research in which team members had been involved. Women either did not know or did not want to reveal household income. Language also proved to be an issue; even though many of the U.S. women were Spanish speakers and all the Mexican women were, some accommodation for language differences (in terms of Spanish vocabulary) was needed on each side of the border. We took care to ensure that our questions were comparable in cultural, as well as linguistic terms. Through regular consultation with our larger research group we were able to identify those health care practices and socioeconomic and cultural issues which perhaps differed in each country, but required careful attention to phrase in a way that would be relevant to the women’s experience.

To ensure accurate data collection, interviewer training sessions were held in Hermosillo and in Yuma, Douglas, and Nogales, Arizona. In Mexico, the clinics had social workers who regularly did intakes. The clinics which were going to conduct this
study all just added a new responsibility: they now had to interview participants and fill out the questionnaire. This posed specific problems to an already overworked and underpaid staff and required constant supervision to maintain the quality of work needed in the research project. Fortunately, many of the social workers and nurses were motivated to participate in the study, both for the training they received as well as the nature of the problem studied.

In Arizona, interviews were a bigger problem as clinics had no staff available and we had to find funding to support interviewers in local clinics. Further, we had to find interviewers who were bilingual, bicultural (the women had to feel comfortable with them), skilled at conducting interviews (meaning skillful at probing for information), and sophisticated enough not to disrupt the smooth functioning of the clinics.

The questionnaires were delivered to the Public Health Office Headquarters in Hermosillo. Logs were kept to monitor and track subject and interviewer response rates. The data manager in Mexico was responsible for receipt of forms and questionnaires from the clinics, supervision of data entry, archiving questionnaires, and maintaining the master database. CDC's Epi Info version 6.0 was used for screen oriented data entry.

TC "Conclusion" Lessons Learned/Recommendations

The key to our successful development and implementation of this project included the following elements:

Diversity of the technical team: Team members came from both sides of the border and represented academic institutions, state public health authorities, and local providers. All of these players were of great importance to the successful implementation of the project.

Participatory decision making with consensus of all players: The entire research project including its design, all protocols, and all instruments were developed, discussed and agreed upon by all team members. Such a process was time consuming and resulted in 12 months for planning the actual implementation of the project. Nevertheless, it was critical to ensuring that all sites would implement a common protocol with common instruments.

Parallel data collection: Once there was agreement on common protocols and instruments, the data collection was implemented in a parallel fashion with supervision for the Sonoran data collection provided by Sonoran team members and supervision of the Arizona data collection provided by Arizona team members. This resulted in clear lines of communication and responsibility for the actual data collection.

Regular communication of team members: The development of the research design and protocols, training plans and evaluation of progress was carried out through regular meetings of the entire team every two months. In addition, conference calls with team members took place on a monthly basis. This regular communication allowed for team problem solving and changes in strategies as the project developed.

Training and Site Visits: Members of the team implemented the training at all sites and had regular site visits to all of the participating clinics. This provided the opportunity to communicate on regular basis with the sites where data was being collected and collectively make decisions regarding any problems. Additionally, it provided the opportunity for additional on-site training in terms of the collection protocols for the samples as well as the questionnaire.

Translation needs: Due to the binational nature of the study, care was given to ensure that translation was available at most meetings and key documents were translated.

The major challenges face by the binational team included the following:

Logistics for distribution of the supplies: As many of the materials for the samples collection were provided by the Arizona institutions HPV kits, Chlamydia kits, brushes, etc., it was a challenge to keep all of eight sites supplied with the necessary materials, and sometimes resulted in having to temporarily postpone the data collection until material arrived. Sending material into Sonora also became complicated with customs regulations.

Logistics for arrival of samples and questionnaires to analysis point: As the study included numerous geographic locations for analyses (University of Arizona in Tucson, HPV samples; ADHS in Tucson, Chlamydia samples; Sonoran State Laboratory, questionnaires), it was difficult to ensure that samples and questionnaires arrived in a timely fashion. For the Chlamydia samples the group was faced with a time sensitive sample that needed to be in the laboratory within five days. The HPV samples had no time sensitivity but required refrigeration in the storing and transport of the samples. Although the correct permits for crossing the border with samples were obtained at the onset of the data collection, it was sometimes very challenging in dealing with local authorities in terms of explanation of the samples and the permits. Finally, the logistics of obtaining the questionnaires from all sites and getting them to Hermosillo for data entry also required more time than anticipated.

Changes in state government: During the course of the project the state government of Sonora had elections bringing changes to the Sonoran Secretaría de Salud Pública and the need to provide information in order to ensure continued support for the project. In Arizona, there was a change of the Director of ADHS also requiring the provision of information to ensure continued support for the project. Occasionally, these changes delayed parts of the research process.

Limitations of the data: With so much time and effort having gone into the development and implementation of the study, it has been challenging to disseminate the results and ensure that
the results are not directly applied to the general population. The nature of the samples (i.e., women who participated in the study were women who were coming in for routine Pap smears) meant that we must be very careful about drawing any broad conclusions from this preliminary work. It does, however, direct us clearly to the next step needed in future research: a population-based sample.

Data have just been analyzed by the entire research team. Data were processed at the Minority Cancer Prevention Program at the University of Arizona under the direction of Anna Giuliano, Jill de Zapien, Mary Papenfuss, and Catalina A. Denman. Data were entered into the computer system at the State Laboratory of the Secretaria de Salud Publica en Sonora under supervision of Catalina A. Denman of El Colegio de Sonora. The entire team is currently preparing a final report as well as a second stage research project addressing women age 40 and older who do not regularly go for Pap smears.

Literature Cited: