



Prioritizing Interventions and Research to Address the Cancer Disparities of Arizona’s American Indian Population

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ABSTRACT

The aim of the Southwest American Indian Collaborative Network (SAICN) is to reduce cancer disparities by closing the gap between community needs and the promise of cancer prevention and cure through participatory education, training and research programs. In an effort to provide evidence-based recommendations and promote the use of relevant data in tribal communities, the SAICN Data and Evaluation Core developed two comparison matrices that present scientifically sound practices for use by community health decision makers in prioritizing activities likely to reduce their respective community’s burden of cancer. In their current configurations, Matrix A considers those cancers for which prevention and early detection interventions exist (cervical, breast, colorectal, tobacco-linked) and Matrix B addresses cancers for which interventions are unknown or not well developed. The matrices were converted into worksheet formats to facilitate their use at the community level. Further, to facilitate the application of this approach in a tribal community setting, guidelines for a five-part implementation plan were developed. In this paper, we describe the matrices and the guidelines and our process for moving forward.

Key Words: Cancer Disparities, Cancer Burden, Matrix

INTRODUCTION

Cancer disparities can be thought of as unequal burdens of this disease caused by differences in rates of incidence and survival. These differences may be the result of both biological and non-biological factors such as exposure to carcinogens, lifestyle characteristics, socio-economic status, access to care and utilization of health care services. The SAICN is a research project, funded by the National Cancer Institute, with an aim of identifying opportunities to address cancer disparities that occur among American Indians in Arizona, Utah, and Nevada.

An important part of the SAICN effort is to assure the active participation of tribal communities in the process of assessing cancer burdens and establishing priorities for their own tribal cancer control

activities. To achieve this objective, the SAICN envisioned three roles for the Data and Evaluation Core (DEC): 1) to encourage community leaders to use relevant data in the selection of topics on which to focus the community's concerns and resources, 2) to encourage movement toward interventions for controllable cancers, and 3) to promote community-based participatory research where knowledge of successful interventions is lacking. In order to accomplish this, the DEC developed a two-step approach that required the creation of a tool that would clearly display the cancer control options available to a tribal community and an implementation plan to facilitate the use of the tool at the community level.

A comparison matrix for community health decision makers was developed that presented scientifically sound actions, along with their costs and benefits. The proposed implementation plan included five phases, beginning with a pilot project and concluding with the dissemination of the results to other tribes. This report describes the prioritization endeavor.

METHODS

An extensive literature search was conducted to compile information on evidence-based cancer prevention strategies. Primary, secondary and tertiary prevention techniques were considered in this compilation. The search focused on the effectiveness, costs and benefits of the interventions identified. In evaluating the appropriateness of the information that was considered and compiled, substantial weight was ascribed to the recommendations of the United States Preventative Services Task Force (DHHS, 2008).

A second component of the literature search concentrated on identifying and measuring the cancer burden among American Indians in Arizona. The Arizona Cancer Registry and the New Mexico Tumor Registry were the primary sources of data used (Arizona Cancer Registry, 2008; New Mexico Cancer Registry, 2008). Additionally, concerns voiced by tribal community members identified seven cancer sites that deserved special consideration. Cancer screening data were considered important in the assessment of the cancer burden and this information was obtained from the Indian Health Service.

With the development of the comparison matrix, it became clear that considerable planning, along with the necessary education of community members, would be essential to effectively use this tool in any community effort to establish priorities for cancer prevention strategies. In a series of meetings, members of the DEC developed an outline and subsequently an implementation plan for using the matrix to prioritize interventions and research to address cancer disparities at the tribal community level.

RESULTS

Table 1 presents comparison Matrix A and Table 2 presents comparison Matrix B. Matrix A is intended to present scientifically sound actions, their costs, and benefits for use by community health decision makers in prioritizing actions that are likely to reduce the community's burden of cancer. The six disparity measures in Matrix A were selected on the basis of their burden on American Indians in Arizona and, more importantly, the availability of evidence-based interventions capable of reducing these burdens. Interventions included the promotion of Pap smears for early detection of cervical cancer, mammography for early detection of breast cancer, and colonoscopy for early detection of colorectal cancer.

The seven disparity measures in Matrix B are cancers for which there currently are no evidence-based intervention strategies. These cancers have been identified as being high priorities for tribal communities in Arizona. Both Matrix A and Matrix B include a column entitled, "Research questions to

ask." These columns allow a community leader to define a research agenda that would further explore risk factors and intervention strategies. Such a specific agenda could be designed to address cancer-related disparities that are of particular concern in the community. Community leaders are ultimately responsible for completing the final column of the matrix and establishing the community's priorities for cancer interventions and research. Based on these matrices, two planning worksheets (available from the authors upon request) have been developed for use in addressing American Indian health disparities in the community setting. One worksheet is designed to help prioritize interventions and the second worksheet is designed to help prioritize research.

To help communities assess their cancer burden and disparities, the matrices are accompanied by a profile of cancer in American Indians in Arizona. The profile includes graphs and tables that display the counts and rates of cancer incidence and mortality by such categories as gender, year, site, stage at diagnosis, and five-year survivorship.

While the comparison matrix tool has not been used or tested in the field, the SAICN project has committed to the use of this approach in an effort to address cancer disparities at the tribal community level. Because the success of the approach will depend on the understanding and acceptance of the concept of prioritizing interventions and research to address cancer disparities, the plan for implementing this approach becomes critical. While the implementation plan cannot be presented in its entirety in this format, as it is quite detailed and complex, the essential elements can be described. SAICN partners will be responsible for assuring that these critical components of the project are implemented.

The first essential element is to identify and select a tribe with the interest, commitment, organizational structure and resources to pilot the implementation plan. The second essential element is to identify, educate and train those members of the community who will be responsible for planning and conducting the community activities required in the application of the matrix prioritization process. This will require an assessment of the cancer-related knowledge of the selected individuals and, if necessary, the tailoring of a training program to develop the necessary competence. The third essential element is for the trained tribal representatives to plan a community-based matrix prioritization program. While SAICN partners may provide technical assistance, it is critical that this planning be done by tribal representatives who are intimately familiar with the history and culture of the tribe. The fourth essential element is to implement the plan. Again, while SAICN partners may provide technical assistance and identify necessary resources, the implementation must be clearly a tribal activity. The final essential element is to review, evaluate and report the results of the program so that other tribes may benefit from the successes, failures and lessons learned.

DISCUSSION

The SAICN project has developed a comparison matrix tool along with guidelines for an implementation plan that can be used by community leaders in addressing cancer disparities with community-based cancer control efforts. The key to the success of this approach will be the role played by community leaders in reaching a consensus on the cancer control priorities of the community. The approach makes clear that for some cancer sites, experts have come to agreement on proven, effective interventions. For many other cancers, however, there are no widely accepted interventions and it is only through further research that effective interventions will be discovered. Therefore, it may be helpful for community leaders to consider cancer control in terms of primary, secondary and tertiary prevention. Primary prevention is the avoidance of cancer by determining what can be done to reduce the risk of developing cancer among members of the community. Secondary prevention involves increasing the likelihood of community members being diagnosed

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Matrix A: List of possible interventions to address American Indian cancer disparities. (The list is in no particular order.)

Cancer Site and Disparity Measure	Scale of Problem in AZ American Indians (4-year avg.) ^a	Potential Interventions	Intervention Metric for American Indians (%; baseline; Target if known)	How well does intervention work? ¹ (USPTF A, B, C, D, E) Additional benefit?	Important cultural aspects to consider (pos or neg)	For an Average-risk Population ...		Research Question to Ask ² Ease of implementation in this pop'n	Priority ³ for Intervention
						Cost and Health Benefit of Intervention	Number to Screen to Save One Life		
Mortality rate slightly elevated; Incidence rate now not elevated in AI for: 1) Cervical Cancer	Invasive cervical cancer cases, 2001-2004: 7	<ul style="list-style-type: none"> Increase utilization of Pap smear; Provide HPV Vaccination; Encourage abstinence 	% women aged 21-64 w/ Pap recorded with the past 3 years = 87.9% (2004-6); AP2010 goal=75% who never had a pap test for those 18 and older within the past 3 years	"A" for women who have been sexually active and have a cervix. Incidence rates in AI dropped in recent years; now are lower than in White pop'n.		\$14,000 per year of life saved from cervical screening at age 20-74 once every 3 years ⁴	1,254 (range 1,140 - 1,367) All ages	What Interventions work?	
Low AI Incidence and mortality rate of: 2) Tobacco-linked cancers	Tobacco-related cancer cases, 2001-2004: Oral: 5 Lung: 18 Bladder: 3	<ul style="list-style-type: none"> Adult smoking cessation programs Youth smoking prevention programs 	% of people 18 and older who are current smokers = 22.1% (2004-6); AP2010 goal=at most 12% of adults aged 18 and older who smoke	"A" for adult programs; "A" for pregnant women; "F" for youth interventions. Reduces heart and lung disease risk.	Some tribes use tobacco in sacred ceremonies.	\$1,100/QUALY saved for adult counseling by clinicians ⁵		Has the attitude about smoking changed among Indian youth?	
Late stage In AIS of: 3) Breast Cancer	Invasive breast cancer cases, 2001-2004: 42	Promote mammography	% women aged 40 and over who had a mammogram in the past 2 yrs = 61.7% (2004-6); AP2010 goal=70% of women 40 and over having a mammogram with the past 2 years	40 for mammography every 1-2 years starting at age 40		\$22,000/QUALY saved for biennial MMSG of women age 50-69 ⁶	691 (range 543 - 838) Age 50+		
Late stage In AIS of: 4) Colorectal Cancer	Invasive colorectal cancer cases, 2001-2004: 25	Promote colonoscopy	% of people aged 50 and over who had a CRC screening=51.3% (2004-6) AP2010 goal=50% screening for those 50 years and older (FOBT with the preceding 2 years & ever had a sigmoidoscopy)	40 for colorectal screening of adults age 50+. Removal of benign polyps reduces cancer risk. Low incidence in AIs leads to false positive screenings. Hard to document a benefit; however, services are well received by families and patients	As in other groups, the topic is rarely discussed.	\$11,900 (range \$7300 to \$22,000) per life-year saved using colonoscopy ⁶	See note. ⁸ 237 (range 42-431) Age 70+; Unknown for Age 45-74	How is colorectal screening performed?	
Utilization of: 5) end-of-life services. (This is difficult to measure or document)	Deaths from all malignant neoplasms: 2004 = 169 2005 = 192 2006 = 177	<ul style="list-style-type: none"> At-home or institutional hospice services Fee-based use of "patient navigators" 	How to measure? Data are needed.		In past, few AIs lived long enough to get cancer. "Death" is difficult topic.	Data are not available.	Not applicable	-Hospice survey for cultural services. -What works?	
High rate of: (other risk factors) 6) [BRFS; special surveys]	Despite high overall BMI, the cancer rates are quite low in AIs.	<ul style="list-style-type: none"> Obesity is linked to cancer of gall bladder, breast, urinary bladder, uterus, kidney, ovary, colon, prostate 	% of adults 18 and over who are overweight or obese=62.2% (2004-6); AP2010 goal=>=15 percent of obese adults 20 years and older	40 for adults. Obesity has proven difficult to control. Modest weight loss lowers risk for diabetes and other diseases.		\$10,000/QUALY saved for physician counseling about physical activity ⁷	unknown		

^a Data Source: Behavioral Risk Factor Surveillance System (BRFSS), 2002-2014 ^b ACR = Arizona Cancer Registry ^c Community leaders will complete these columns.

Matrix B: Lesser opportunity cancers (The list is in no particular order.)

Disparity Measure	Scale of Problem in American Indians (4-year avg.) ^a	Risk Factors; Potential Interventions	Intervention Metric for American Indians (%; baseline; target)	Relative Effectiveness of Intervention (high-med-low)	Relative Cost and Benefit of the Intervention	Research Question to Ask?	Priority for	
							Intervention	Research
Relatively elevated incidence rate of: 7) Liver Cancer	Invasive liver cancer cases, 2001-2004: 13	<ul style="list-style-type: none"> Alcohol avoidance; CAGE questionnaire Hepatitis B Immunization Screen for Hepatitis C 	Not applicable	Unknown; This is under study in the U.S. Asian Population.	unknown			
Incidence rate of: 8) Melanoma of skin	Invasive cutaneous melanoma cancer cases, 2001-2004: 4	<ul style="list-style-type: none"> Reduce sun exposure, especially in childhood 	Not applicable	unknown	Not applicable			
High incidence rate of: 9) Kidney and renal pelvis Cancer	Invasive kidney & renal pelvis cancer cases, 2001-2004: 33	<ul style="list-style-type: none"> No proven intervention; needs research 	Not applicable	Not applicable	Not applicable			
Incidence rate of: 10) Pancreas Cancer	Invasive pancreas cancer cases, 2001-2004: 12	<ul style="list-style-type: none"> No proven intervention; needs research 	Not applicable	Not applicable	Not applicable			
Incidence rate of: 11) Prostate Cancer	Invasive prostate cancer cases, 2001-2004: 30	<ul style="list-style-type: none"> Early detection has not been shown to prolong life Many local cancers do not progress 	unknown	Unknown See the separate write-up on this topic.	Not applicable			
Incidence rate of: 12) Stomach Cancer	Invasive stomach cancer cases, 2001-2004: 14	<ul style="list-style-type: none"> Avoid alcohol, tobacco, and pickled or salty foods Screen for Helicobacter pylori 	Not applicable	Not applicable	Not applicable			
Incidence rate of: 13) Gallbladder Cancer		<ul style="list-style-type: none"> Risk factor = gallstones and obesity 	Not applicable	unknown	Not applicable			

^a ACCR = Arizona Cancer Registry

^b Community leaders may complete these cells.

in the earliest stage of cancer through early detection and screening. Tertiary prevention requires providing appropriate care, once diagnosed, to avoid complications of treatment and to maintain a high quality of life.

It is important to discuss these issues and the variety of opinions that they will elicit because of the different ways that stakeholders view opportunities. Some may want to improve local programs or services, others may want to increase program utilization, and yet others may want to focus on health behaviors. These discussions will be guided by the profile of cancer in American Indians in Arizona. For instance, the incidence rate for all cancer sites is lower in American Indians in Arizona than the rate in the general population. Also, the data show that American Indians have the lowest rates of breast, colorectal, prostate and lung cancer when compared to other groups in Arizona. However, American Indians have among the worst outcomes for five-year survivorship for breast and colorectal cancer, and data on breast cancer show that American Indians are diagnosed at a later stage compared to other race/ethnic groups.

The leaders implementing this plan, and the community, must determine how these data can be used to prioritize efforts to reduce disparities. They must determine whether prioritizing means making a choice between investing in primary, secondary, or tertiary prevention. Some of these choices will not be easy because so little is known about the cost benefit ratio of promoting interventions in low-incidence populations. Further, most tribal communities in the Southwest have younger populations than those in the general population and the effect of this difference on prevention and intervention strategies is not known. These unknowns, along with others yet to be identified, will be both a challenge and a learning process for those communities that embark on an evidence-based cancer control program. Consequently, it will be important to evaluate the role of the matrix approach in addressing cancer disparities at the tribal community level.

CONCLUSION

Leaders of tribal communities concerned with a variety of health disparities and critically limited resources, face a particularly challenging task should they choose to establish a cancer control program. The SAICN project has addressed this need by developing a comparison matrix approach along with guidelines for implementing the use of this approach to set priorities for interventions and research at the community level. While this approach has yet to be used and evaluated in the field, it does provide a unique concept for addressing cancer disparities. The SAICN project proposes to select a tribe to conduct a pilot study that will use the matrix concept to evaluate its effectiveness in responding to the cancer concerns in a tribal community.

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- The New Mexico Tumor Registry ascertains the cases treated within the facilities of federal Indian Health Service. These confidential data are exchanged with the Arizona Cancer Registry.

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