Developing the National Institute for Occupational Safety and Health's Cancer Control Demonstration Projects for Farm Populations

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ABSTRACT: *Although farmers experience lower overall cancer rates than the U.S. population, they are at increased risk for cancers of certain sites, such as brain, stomach, lymphatic and hematopoietic, lip, prostate, and skin. Little research has been done to determine the extent to which farmers and their families use cancer control services or how their utilization behaviors and cancer survival rates compare to those of nonfarmers in the United States. In 1989, recognizing the occupational uniqueness of farm populations and the limited cancer-related information about them, Congress mandated that the National Institute for Occupational Safety and Health (NIOSH) develop a program to promote cancer control among farming populations. Eight institutions were funded through cooperative agreements to collaborate with NIOSH and each other to develop the demonstration research and intervention projects. The projects are aimed at identifying barriers that prevent farmers, farmworkers, and their families from accessing the full range of cancer control services, and then implementing interventions to mitigate those barriers. This paper illustrates some of the conceptual and methodological issues NIOSH researchers and their collaborators faced while developing the cancer control program.*

Farmers and farmworkers are a medically understudied and, in some cases, an underserved population. Although farmers experience lower overall cancer rates than the U.S. population, they are at increased risk for certain site-specific cancers, such as brain, stomach, lymphatic and hematopoietic, lip, prostate, and skin (Blair, et al., 1985). In addition, compared to urban populations, rural cancer patients are more likely to be diagnosed at later stages of disease, are more likely to be unstaged at diagnosis, and are at a more advanced stage of illness when referred to home health care agencies (Monroe, et. al., 1992; Liff, et. al., 1991).

Although there are some data on health service utilization among rural residents (Office of Technol-

ogy Assessment [OTA], 1989), there is little that specifically reflects health service utilization practices of farmers. To more fully address the health needs of farmers and farmworkers, the National Institute for Occupational Safety and Health (NIOSH) developed the Cancer Control Demonstration Projects for Farming Populations.

Little research has been done to determine the extent to which farmers (including farmworkers) and their families use cancer control services or how their utilization behaviors and cancer survival rates compare to those of nonfarmers in the United States. Recognizing the occupational uniqueness of farm populations and the limited cancer-related information about them, Congress, in 1989, mandated that NIOSH develop a program to promote cancer screening among farmers in the upper Midwest. This mandate was broadened to include the development of a range of cancer control efforts, including primary (knowledge of cancer prevention and risk factors), secondary (screening and early detection), and tertiary (treatment and follow-up) prevention. The objectives of the program were to identify barriers that prevent farmers and their families from accessing the full range of cancer control services and to implement interventions to mitigate those barriers.

Cancer Control Defined

Cancer control is defined as "the reduction of cancer incidence, morbidity, and mortality through an orderly sequence from research on interventions and their impact in defined populations to the broad systematic application of results" (Greenwald, 1984; Breslow, 1979). The process of developing cancer control programs for farmers brought with it some difficult conceptual and methodologic issues. These included questions on the definitions of "farmer," determining appropriate comparison populations, determining which cancers were amenable to which interventions, and determining the appropriateness of underlying theoretical models and study designs to assess interventions.

Eight institutions were funded through cooperative agreements to collaborate with NIOSH to address these issues and to develop the research and intervention demonstration projects. The process of translating a Congressional mandate into a potential public health program, and implementing that program on a broad scale, provided unique opportunities and methodologic challenges. The papers in this special issue are largely the result of this process.

Since 1990, the Mercy Hospital System of Central Iowa, National Farm Medicine Center at Marshfield Clinic of Wisconsin, Michigan State University, University of Minnesota, Georgia Department of Human Resources, Nebraska Department of Health, the Western Consortium of Public Health (California), and Program for Appropriate Technology in Health (Washington, D.C.) were awarded funds to collaborate with NIOSH to conduct the cancer control demonstration projects. These projects will continue through 1997. The programs target diverse farming populations in 12 states. Given the nature of cancer as the condition of interest and the lengthy period between its initiation and clinical diagnosis, evaluation of the effectiveness of the interventions focused on intermediate outcomes, such as changes in knowledge, attitudes, behaviors, and practices, that might ultimately lead to reductions in the levels of cancer morbidity and mortality in the targeted populations.

Shaping the Cancer Control Demonstration Projects

The mandate for the projects initially focused on providing screening for various cancers in farmers. However, a broader view was adopted for a number of reasons. A critical review of the cancer screening literature indicates that few occupational cancers are amenable to screening. Moreover, screening using an untested modality could result in a large number of false-positive results. The history of cancer control efforts shows that cancer screening should not be viewed as an independent activity. Rather, screening should be seen as part of a continuum of cancer control services that includes the provision of information on risk factors, access and use of early detection for symptomatic patients, and screening for asymptomatic individuals; receipt of timely treatment; and effective rehabilitation and follow-up (Breslow, 1975; Greenwald, 1984; Greenwald, et al., 1985; Greenwald & Sondik, 1986).

The problems with viewing cancer screening outside this context are four-fold. First, of the few cancers shown to be amenable to screening in asymptomatic individuals, breast and cervical cancer and, to some extent, colon cancer are the most defensible.

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Second, screening asymptomatic individuals with modalities that have not been tested in intervention trials can lead to large numbers of false-positive results and extensive follow-up costs (National Cancer Institute [NCI], 1991; U.S. Preventive Services Task Force, 1989). Third, screening with unproven modalities also could lead to excess anxiety for those screened. Fourth, for groups such as migrant farmworkers, there was little that could be quantitated in terms of follow-up since the workers generally lived outside the upper Midwest farming regions and returned home after a working season. For these reasons, it was decided that cancer screening would represent only one facet of the program and that the demonstration projects would be recast in the broader context of cancer control, thus more effectively demonstrating ways in which farming populations can access cancer control services more fully.

The dearth of research focusing on the knowledge and practices of cancer prevention and treatment within farm populations made it difficult to know what types of programs would meet the specific cancer-related needs of farmers and their families (Monroe, et al., 1992). Thus, NIOSH and its collaborators developed the cancer control projects to: (1) affect the maximum number of farmers as quickly and as cost-effectively as possible by using networks of existing rural nonprofit hospitals that have access to both the latest diagnostic equipment and board-certified oncologists; (2) increase preventive behaviors and awareness about cancer control measures, such as knowledge of signs and symptoms pertaining to cancer; (3) promote adherence of asymptomatic individuals to cancer prevention and early detection programs; and (4) promote cancer control awareness among rural health care providers

General Issues

A number of general issues became apparent as the interventions moved into the planning and implementation stages. First and foremost was how to define "farmer." Farming is a heterogeneous occupation. Some farmers are full-time owner-operators of farms, who may work the farms with assistance from migrant and seasonal farm laborers and other farm employees, with their families, while other farmers are managers or employees in large agri-businesses or are hired migrant or seasonal farmworkers or nonmigrant farm employees. Many owners (and family members) of small farms may also work outside the farm, perhaps in urban or other nonrural areas. Consequently, they may have a range of potentially nonfarm-related carcinogenic exposures. Also, they may have the opportunity to participate in various urban-based health care systems that might be different than rural systems.

Owner operators, resident hired farm employees, and migrant workers may differ in terms of behaviors, attitudes, and opportunities to access services. Depending on the characteristics of specific farm populations, the cancer-control knowledge, attitudes, and behavior of farmers span a broad spectrum.

In the end, each collaborating institution defined its farming population as it saw fit to meet the needs of its research model. In most instances, the definitions were broad, and generally farmer was defined as someone who lives and works entirely or partially on a farm and whose duties are related to the cultivation of land, crops, or livestock. This definition included individuals who met that definition but also who had nonfarm jobs in addition to farming.

In addition to the general definition of farmer was the need to determine if there were gender-specific job tasks and behaviors. This was due to the fact that cancer risks have been shown to be differentially related to gender, and the barriers to cancer control may, in some cases, be gender specific as well (Zahm, et al., 1993). Moreover, because of the unique relationship between occupation and lifestyle that typifies farmers, the focus of interventions for farmers should involve the entire farm family. The demonstration projects described in this issue, therefore, involve farmers, their spouses, and, in several cases, their school-age children. Ultimately, each collaborating institution determined the appropriate comparison group and the proper research units, based on each institution's specific research goals.

One issue faced by NIOSH and its collaborators was which cancers should be the focus of the projects. Should the program focus only on the cancers for which farmers are at increased risk (many of which are not amenable to early detection methods), or should other cancers (more of which have been shown to be amenable to known early detection modalities such as breast and cervix) also be included? It was decided that since farming is both an occupation and a lifestyle, farmers, farmworkers, and their families may access cancer control services differently than their rural nonfarm and urban counterparts. Therefore, targeting a wider variety of cancers would be valid, since the program's ultimate

goal was to demonstrate ways to reduce cancer morbidity and mortality among farming populations.

Development of Research on Barriers to Cancer Control

Study Designs. A critical question in designing evaluations of the intervention was who should be in the comparison groups. Should farmers be compared with urbanites or rural nonfarmers? In the former case, farming and rurality may be confounded; in the latter case, this confounding might be resolved, but the barriers for the two groups may be the same since both are faced with the limitations inherent in "rurality." Ideally, the use of four categories—farm, nonfarm, rural, and urban—would allow for identifying farming-specific barriers from rural or urban barriers.

Three basic designs were used in the studies. The following comparisons were made:

- surveys were administered to farmers and urban and rural nonfarmers to compare their knowledge, attitudes, and behaviors toward cancer risk factors, screening, and treatment;
- cases of cancer among farmers were compared to cancer cases among urban and rural nonfarmers in terms of cancer stage at diagnosis, treatment required, and survival; and
- cancer incidence and mortality rates were compared among farm and urban and rural nonfarm populations.

Development of Survey Instruments. If survey instruments are to be useful in identifying barriers to cancer control faced by farmers and their families, those instruments need to be tailored to farmers. An iterative process of survey design, focus group testing, pretest, and revision is generally considered useful (Patton, 1990). Survey instruments were tailored to address farmer-specific issues. Questions from previously validated instruments, such as the Cancer Control Supplement of the National Health Interview Survey and the Behavioral Risk Factors Survey, were included in the surveys of barriers. This allowed for analyses comparing farmers in the Midwest to those nationwide.

Content areas for barriers surveys varied but generally focused on knowledge, attitudes, and behaviors of farmers regarding carcinogenic exposures, other risk factors, appropriate screening modalities, and recommended follow-up procedures. This information is useful, but it generally reflects the demand side of the health care equation. Research should also consider supply-side factors, such as the organization of health resources in farm communities and availability of regional facilities. For example, a barrier to the delivery of cancer care to farm populations is the lack of linkage between rural health care providers and regional cancer specialists. This is in part due to the fact that community resources for delivering comprehensive care are diminishing, resulting in hospitals being left without specialty resources and technical equipment. In addition, many rural practitioners are generalists and are not able to keep current in cancer care for the many tumor types.

Development of Interventions to Overcome Barriers to Cancer Control. The major focus of the demonstration efforts is the development of interventions that enable farmers to mitigate or overcome barriers to cancer control. The development of these interventions is based on the premise that cancer mortality can be reduced by effective application of known and proven cancer control services (Greenwald, 1984). Thus, the NIOSH program involved the application of known intervention modalities shown to be effective and capable of being translated to farmers and their families.

NIOSH strongly encouraged its collaborators to develop and use primary prevention interventions. Therefore, education and information dissemination about cancer risk factors and preventive behaviors are common elements of the intervention projects. These programs are targeted to farm families, school children, handlers of pesticides, 4-H and FFA clubs, and rural physicians, pharmacists, veterinarians, and other rural health practitioners. Some of the more innovative programs include the provision of nutritional information to farmers through rural supermarkets, a campaign to increase consumer purchase of fruits and vegetables in an effort to reduce colorectal, stomach, and other cancers; programs to modify primary care practitioners' office practices to include cancer prevention and early detection activities (i.e., counseling and scheduled screening examinations) and encouraging veterinarians to provide farmers with human cancer control information. Physician promotion of cancer prevention information and materials may not be limited by knowledge deficits or problems with physician attitudes or beliefs. Rather it may be office management practices that hamper information dissemination and referral

(Pommerenke & Smart, 1992; Orleans, et al., 1985; Dietrich, et al., 1992).

Key to the development of the interventions was the requirement for developing evaluation strategies prior to implementing the intervention strategies. Most of the components of the interventions were designed so that the effectiveness of the intervention could be evaluated in a relatively rigorous manner. Assessment of content, process, impact, and effectiveness were performed in a variety of ways. Some of the projects compared results from baseline and post-intervention surveys; some compared intervention (target) county farm household data to data from households in control counties that did not receive interventions. Some evaluations measured changes in knowledge, attitudes, and behaviors. Still others conducted assessments in the context of focus group discussions.

The projects were reviewed by a group of external experts, and, early on, the most common criticism was that the projects were too ambitious for the time frame (usually three to four years) and the availability of ongoing funding. Additionally, it was felt that the barriers surveys and the interventions had to be more specifically tailored to the target populations. In response to such criticism, many of the projects attempted to obtain relevant input about the design of interventions from representatives of the study cohorts. Efforts were made to obtain information from farmers, extension service agents, local physicians, health care providers, insurance agents, and cancer specialists.

The Issue of Theory-based Interventions. A typical problem in intervention research is that most of the interventions are not theory driven. The attitude of researchers often is to use the "try something and see if it works" approach. Such research does not specify in advance the chain of effects by which specific interventions are expected to influence identified risk factors and outcomes (Coie, et al.,1993). Interventions will be most powerful when they are devised from tested theories (Goldenhar & Schulte, 1996).

Initially, only one of the five collaborative projects described in detail the theoretical basis of its intervention and how each construct would be put into operation. Using the models, the researchers were able to discuss their hypotheses regarding the relationships between various independent variables, as well as between independent and dependent variables. These hypotheses then could be tested explicitly using the collected data. Researchers on one of the projects described their theoretical foundation but did not take it further in terms of construct and hypothesis development.

In most projects, objectives were put forth, but only the project whose goal it was to test models identified specific, testable hypotheses. Without testable hypotheses, the project becomes an educational intervention where change can be assessed but the context and implications of these changes cannot be well understood. In the case of the NIOSH cancer control program, attempts were made to ensure theory-driven research models and interventions planning. Admittedly, the projects have become more rigorously designed as the program was expanded over the past five years.

The philosophy of cancer control research is that there is a hierarchy of approaches and scales that follows "an orderly sequence of research on interventions and their impact in defined populations to the broad systematic application of research results" (Greenwald, 1984). NCI has formulated five research phases for cancer prevention.

1. *Hypothesis development* uses laboratory, epidemiological, and clinical data to postulate testable cancer control intervention hypotheses.
2. *Methods development* tests (validates) intervention methods and research instruments used to test these hypotheses.
3. *Controlled intervention trials* test the hypotheses using validated methods to establish the efficacy of an intervention.
4. *Defined population studies* apply effective intervention strategies to sizable, well-characterized populations to obtain valid inferences that can be generalized to an entire target population.
5. *Demonstration and implementation* applies interventions previously justified by the first four phases. These interventions are applied to community-sized target populations to demonstrate reduction in cancer rates or risk factors.

NIOSH staff attempted to ensure that proposed projects were defined with respect to these phases, but the projects often overlapped a number of phases.

Evaluations

Perhaps the most problematic issue related to evaluation was that the projects had to be conducted

extramurally with a mandated three- to four-year time frame. Clearly, it is not possible to demonstrate a direct effect on cancer morbidity and mortality in such a short period. Thus, approaches were mostly confined to using intermediate outcomes such as changes in knowledge, attitudes, behaviors, and practices. The assumption has been that positive changes in these variables would ultimately decrease cancer rates.

Many of the projects used pretest/post-test designs to evaluate interventions. This is generally a weak design because confounding factors make it difficult to make decisions about causal inferences with any confidence. A randomized control design is most preferred but unlikely in community intervention research. Thus, quasiexperimental designs controlling for confounders are used (Cook & Campbell, 1979). There were also concerns that in some cases there might be contamination or overlap between target and comparison areas so that the messages of interest went to part of the comparison areas as well as the target area. More rigorous evaluation designs are needed if the effectiveness of interventions is to be assessed.

Both process and outcome evaluation approaches were used. Process outcomes often are quite useful, but their utility often is undermined by poor design. For a process evaluation to be helpful it needs to be thorough, accounting for all relevant aspects of the process. Good documentation of the entire process is essential.

Conclusion

Farmers are not a homogeneous population. There are various segments within agricultural populations (e.g., farmers, ranchers, foresters, migrant and seasonal farmworkers), and these groups (as well as individuals within groups) may have different characteristics affecting the way each seeks health information and care and the extent to which each practices healthy behaviors. Also, socioeconomic status and education levels vary among farm populations. The extent to which these characteristics may vary will affect how different groups of farmers access cancer control services. There is a need to distinguish between types of farmers in this regard, so that specific cancer interventions may be developed.

This issue of *The Journal of Rural Health* includes descriptions of components of the NIOSH Cancer Control Demonstration Projects for Farm Populations and is not meant to be a comprehensive review of the projects in their entirety.

One goal of the overall effort was to identify cancer control approaches generalizable to other regions within the U.S. The degree to which these findings are generalizable will depend on the similarities in groups living in other regions, the barriers specific to the regions, and attitudes within those regions. Although farmers have a number of common features, differences by farm type, size, and region may influence the effectiveness of cancer control programs.

Furthermore, the nature of agriculture is changing. Agriculture is being restructured to include not only more agribusinesses but also more highly efficient small farms (OTA, 1992). This restructuring needs to be considered in the context of cancer control service utilization because the extent to which health insurance is available is affected by the size and nature of the farming endeavor (Coburn, et al., 1994). Equally important may be restructuring of the health care system and the pursuant implications for cancer control among farmers.

Many conceptual and methodologic issues arose in the development of the cancer control programs for farm populations. At present, other than the barriers to cancer control data collected as part of this NIOSH program, there is only a small database extant about the cancer-related knowledge, beliefs, attitudes, and behaviors of farmers and their families. This series of projects was designed to assess the barriers farmers face in obtaining cancer control services, as well as to implement interventions to overcome these barriers. Some of these barriers pertain to the farmers themselves, some to their occupations and lifestyles, and some to the health care system in general. The project components presented in this issue reflect a concerted effort to demonstrate that farming populations as an occupational group can reduce its risk of cancer morbidity and mortality by increasing its access to cancer control services.

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