Communicating Research to the General Public

At the March 5, 2010 UW-Madison Chemistry Department Colloquium, Prof. Bassam Z. Shakhashiri, the director of the Wisconsin Initiative for Science Literacy (WISL), encouraged all UW-Madison chemistry Ph.D. candidates to include a chapter in their Ph.D. thesis communicating their research to non-specialists. The goal is to explain the candidate's scholarly research and its significance to a wider audience that includes family members, friends, civic groups, newspaper reporters, program officers at appropriate funding agencies, state legislators, and members of the U.S. Congress.

Over 50 Ph.D. degree recipients have successfully completed their theses and included such a chapter.

WISL encourages the inclusion of such chapters in all Ph.D. theses everywhere through the cooperation of Ph.D. candidates and their mentors. WISL is now offering additional awards of $250 for UW-Madison chemistry Ph.D. candidates.

Wisconsin Initiative for
Science Literacy

The dual mission of the Wisconsin Initiative for Science Literacy is to promote literacy in science, mathematics and technology among the general public and to attract future generations to careers in research, teaching and public service.

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Rural Cancer Disparities and Communication Needs

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Chapter 7: Summary for a General Audience

I wrote this chapter to share my research with a general, non-scientific audience. It is my philosophy that scientists should not only do research to improve the health and wellbeing of the public, but also ensure our findings and the importance of research are widely communicated. I would like to thank the Wisconsin Initiative for Science Literacy at UW-Madison for providing this platform, and for sponsoring and supporting the creation of this chapter.

Cancer in Rural America

My research focuses on reducing the burden of cancer in rural America. As our understanding of and technology to prevent, detect, and treat cancer has improved, fewer people in the US have developed or died from cancer. However, some populations have had smaller improvements. Specifically, rural America has relatively more cancer deaths compared to urban America. To understand why people in rural America fare worse in cancer outcomes, it helps to understand what factors (individual or environmental characteristics) increase the risk of getting cancer or dying from cancer, and what these factors look like in rural America. In this chapter, I will share how my research helps us understand and address factors related to cancer outcomes in rural America.

Factors that increase the risk of getting cancer or dying from cancer fit into two categories: non-modifiable and modifiable risk factors. Non-modifiable risk factors are things we cannot change, such as genetics. For example, some women are born with BRCA genes and therefore have a higher risk of developing cancer. Non-modifiable factors are important to study to know what populations may be more likely to develop or survive cancer. Modifiable risk factors, on the other hand, are things we can change to reduce our risk of getting cancer or improve our chances of surviving cancer. For example, we can change certain behaviors, such as limiting our exposure to carcinogens (substances that cause cancer) or getting screened for cancers to catch and treat them earlier. Modifiable factors are important to study so we can address or change them, which ideally leads to fewer people developing or dying from cancer. The focus of my research is these modifiable factors.

Individuals in rural America and public health workers can address modifiable risk factors to reduce cancer risk and death. In the example of breast cancer, routine mammography screening can detect cancer early, leading to earlier treatment. Infrequent screening may find cancer at a later stage, which increases a patient's risk of death. However, fewer rural women have had a recent mammogram compared to urban women, and this may be part of the reason why more rural women are diagnosed with breast cancer at a later stage. To ensure individuals in rural America have the ability to take actions that can lower their risk of cancer or increase their likelihood of successful treatment, I conducted studies that can help us understand what influences these cancer behaviors.

Influences on Cancer Behaviors

Researchers have developed models to understand what influences behaviors. According to these models, there are internal and external factors that affect our ability or intention to do a behavior. External (outside or non-personal) factors include environmental, geographic, and financial contexts in which an individual lives. For example, travel time to a clinic from a rural area may impact someone's ability or decision to get a cancer screening. Internal (inside or personal) factors are related to how we perceive or process information. These include, but are not limited to: the knowledge we have about cancer; how likely we think it is that we will get cancer; how much control we believe we have over a cancer outcome; how worried we are about cancer;

what sources (such as people, books, websites) we go to first for information about cancer; and how much we trust the source or person giving us information about cancer. To ensure individuals can make informed health decisions, messages about cancer can address internal influences on cancer behavior and acknowledge external factors.

As an example, breast density notification laws require patients to be informed about their breast density so they can make informed health decisions about breast cancer screening. Breast density notifications are messages sent by a clinic following a mammography screening with information about breast density, the impact breast density has on the ability for a mammogram to find cancer, and sometimes information about breast density's impact on breast cancer risk. Breasts are made up of fatty tissue, glandular tissue (the parts that make and carry milk), and fibrous tissue (connective tissue that holds the breast in place). Fibrous and glandular tissue are also called fibroglandular tissue. About 40% of women over age 40 have dense breasts, which means they have fibroglandular tissue throughout their breasts (sometimes called heterogeneously dense or extremely dense). On a mammogram, fatty tissue looks dark, and fibroglandular tissue looks white. Unfortunately, cancers also appear white. In dense breasts with more fibroglandular tissue, it is harder to see and catch cancer on a mammogram. Dense breasts also create an environment in the breast that increases the risk for cancer.

However, most government health organizations and medical societies do not recommend women with dense breasts get screened more often or get different tests unless they have other factors that put them at high risk for breast cancer. This is because more frequent screening and using additional tests other than mammography has not led to fewer breast cancer deaths. Instead, increased screening may find small, non-fatal breast cancers. Getting more breast cancer screening may have negative outcomes, such as causing anxiety or worry (internal factors), and increases the amount of time and money a woman spends on health care (external factors). External factors such as time to a clinic, and internal factors such as personal values, perceptions, and knowledge about benefits and harms of cancer screening are important for women to consider when making decisions about breast cancer screening.

Researchers know that knowledge and perceptions may be different for women from different racial and ethnic groups, or for women with different education and income levels. However, there is less research on whether rural and urban women differ in their knowledge and perceptions. To ensure people in rural areas have the information they need to make decisions about behaviors related to cancer (such as breast cancer screening), we need to study rural populations and their perceptions and knowledge about cancer (internal factors) and the greater context (external factors) that may impact their ability to do those behaviors.

How My Research Addresses Rural Cancer Disparities

I researched how perceptions and knowledge about cancer relate to an individuals' behaviors related to cancer, such as getting or intending to get breast cancer screening. I studied disparities (differences) between rural and urban populations because rural America has had smaller improvements in lowering the number of cancer deaths. By understanding rural individuals' knowledge and perceptions about cancer, and placing these in context of external factors that impact behaviors, I can make suggestions for what information rural individuals may need for making cancer behavior decisions.

In my studies, I used methods and knowledge from the fields of epidemiology and health communication research. Epidemiologists study diseases, such as cancer, and how populations are affected by them. Health communication researchers study messages and strategies that can inform people's health decisions. In my studies, I used principles of epidemiology to examine cancer outcomes and individuals' behaviors in rural populations. I also used health communication models to study what knowledge and attitudes communicators can address in health messages. The goal of my research is to help create cancer communications that address rural populations' cancer information needs. Ultimately, we can create messages that enhance rural individuals' knowledge and ability to make informed health choices surrounding cancer prevention, screening, and care.

In my first study, I looked at survey data from women across the US. Respondents were asked about their perceptions on cancer and how they would prefer to get cancer information. I studied whether these perceptions might make them more likely to get a mammography screening. I also examined whether urban and rural women had different perceptions about cancer that health communicators could address in cancer messages.

In my second study, I looked at another set of surveys from women in states with different kinds of breast density notification laws. The breast density notification laws ensure that women with dense breasts receive a message from the clinic following a mammogram about implications for breast cancer and screening. However, some states require that all women, regardless of their breast density on a mammogram, receive them. I compared women from rural and urban areas, and compared women from states that send breast density notifications to all women and only women with dense breasts. I studied whether women had different knowledge and attitudes about breast density and its impact on breast cancer risk and screening. I used my findings to make suggestions for future cancer messages about breast density.

In my final study, my research team conducted interviews with rural Wisconsin community health care partners and cancer researchers about their perceived barriers and resources for reducing cancer, such as cancer risk behaviors, screening, and treatment. I analyzed interviewees' responses to see if there were common knowledge and perception issues that health communicators can address in rural populations. The study team also asked about barriers and resources to doing cancer research with rural communities, and not just in them, to further improve our understanding of rural cancer disparities and how to address them.

My Findings and Suggestions for Cancer Communications to Rural Communities

Based on results from my research, women who worry more about cancer, or who believe there is more they can do to lower their risk of getting cancer, are more likely to have had a mammography screening. However, even if a woman believes there are things she can do to lower her risk of getting cancer, there may be factors related to living in a rural area that affect a woman's ability or intention to get a mammogram. Women are also more likely to have had a mammogram if they trust their doctor, with 65% of women from nonmetropolitan (rural and smaller urban) areas preferring doctors as their primary source of cancer information. I also found that about 6 or 7 out of 10 women know that dense breasts make it difficult to see cancer on a mammogram, regardless of where they live or whether they received a breast density notification from their clinic following a mammogram. However, fewer than 2 out of 10 women know that dense breasts increase the risk of breast cancer. About 1 in 3 women would want additional breast cancer screening if they had dense breasts, which most cancer organizations do not currently recommend. Based on these findings, women could benefit from more information about breast density and its impact on breast cancer risk, as well as what frequency of screening cancer organizations recommend. Most women in rural areas may prefer to receive information about cancer from their doctors. It may be important for such communications to acknowledge women's worry about cancer while also highlighting actions they can take to reduce the risk of cancer.

I also found that individuals in rural Wisconsin have gaps in cancer knowledge and have certain attitudes that may prevent them from doing behaviors to reduce their cancer risk. Barriers to reducing rural cancer occurrences and deaths include: not knowing about cancer risk factors; stoicism and not going to the doctor for preventive care or cancer screenings; social norms such as alcohol consumption and smoking, which can increase the risk of developing cancer; and mistrust in researchers or clinical cancer trials. Cancer researchers also find it difficult to do research with rural communities because of lack of time, funding, and the amount of effort it takes to create mutually beneficial and trusting relationships with the communities. Rural community members suggested that future cancer messages address specific knowledge gaps and attitudes often held by people in those rural communities. Communications to rural populations about cancer could focus on prevention and screening information, and could acknowledge culture and attitudes that are relevant to rural individuals. Rural cancer research may also be increased by providing more incentives and resources for collaborative research. For example, researchers early in their career may be better able to do cancer research with rural communities if they can work with existing partnerships or funding, and are encouraged to build trust with rural populations.

Next Steps

An important note about my research is that it provides health communicators with information about what knowledge and perceptions are related to rural individuals' cancer behaviors. However, I cannot make conclusions about whether individuals' knowledge or perceptions actually lead to behaviors, such as getting a mammogram. This is because the surveys I used asked about knowledge and perceptions at the same time as they asked about behaviors. My studies can conclude, for example, that women who have had a mammogram are likely to have more worry about cancer compared to women who did not have a mammogram, but I cannot tell if the worry about cancer directly leads to getting a mammogram. Future research needs to initially survey rural individuals about their current knowledge and perceptions related to cancer, then later ask follow-up questions about what behaviors they did (for example, getting a mammogram) and whether their knowledge and perceptions changed since the initial survey.

Another important takeaway from my studies is that we need more research and collaboration with rural communities to better understand their communication needs. These studies included a smaller number of people from rural compared to urban areas, and it is hard to tell whether the differences I found between rural and urban groups apply to all US populations. To better understand different experiences among people living in the rural US, we need studies that recruit more rural individuals. Researchers have surveyed specific subgroups of the rural US, such as Black and Hispanic rural individuals, and it is important that researchers continue to work with minority rural communities to better understand the cancer outcomes and communication needs of specific populations. While my research provides an initial understanding of the burden of cancer in rural America and the communication needs of rural individuals as a general population, it is important to ensure the benefits of this research reach all rural individuals in the US.

My final takeaway for future studies is the importance of working across disciplines. Culture, knowledge, and attitudes can affect individual decisions about behaviors related to cancer, and should be studied alongside factors such as and rurality. Epidemiologists can study cancer outcomes (such as prevention, screening, and care) in rural populations. Health communication researchers can study the knowledge and attitude factors affecting behaviors, and provide guidance on messages about cancer to rural populations. Finally, working directly with rural communities is important for understanding priorities, resources, and barriers to lowering cancer risk and death in rural America. By working across disciplines and involving rural stakeholders, the broader context of rural cancer can be understood and addressed with messaging specific to rural populations.