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Centers of Excellence in Cancer Communication Research (CECCR) Midcourse Update

Harnessing the Information Revolution to Help Reduce the Cancer Burden

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Acknowledgments

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Foreword

The National Cancer Institute (NCI) has an important leadership role in the science and practice of communication. To complement and inform our service programs, we need to know more about the science of bringing our messages to the public–whether on tobacco use, the importance of cancer screenings, the contribution of basic science, or the complexities of cancer diagnosis and treatment.

In a recent report, the directors of NCI's Comprehensive Cancer Centers clearly concurred, recommending NCI "expand health communications research to improve understanding of which communications approaches… are most effective with specific populations to prevent and control cancer."

Bringing evidence to the practice of communication has never been more important. We are facing radical changes in our information environment: Multiple information sources often disseminate contradictory or inaccurate information; the digital divide threatens to widen; and information simply does not exist for the younger generation if it is more than a few clicks away.

We at NCI believe that it is essential for cancer communication research to be part of an interdisciplinary approach to cancer prevention and control, to maximize the impact of exciting medical discoveries throughout the NCI research community. Therefore, one of our priorities in *NCI's Strategic Plan for Leading the Nation* is to integrate social, psychological, and communication research with biological research.

The cornerstone of NCI's investment in an interdisciplinary approach to communication research is our Centers of Excellence in Cancer Communication Research (CECCRs) at the University of Michigan, the University of Pennsylvania, Saint Louis University, and the University of Wisconsin. This initiative is funded through the Health Communication and Informatics Research Branch in the Behavioral Research Program of the Division of Cancer Control and Population Sciences.

I am pleased to issue this *Midcourse Update: Harnessing the Information Revolution to Help Reduce the Cancer Burden,* which provides a glimpse into the evidence being generated by interdisciplinary teams of researchers of the CECCRs. The science they are building promises to offer breakthrough discoveries such as predictable methods for effectively and efficiently personalizing cancer communication messages and online systems. Communication research described in this *Update,* together with our diverse portfolio of biomedical research, holds the promise of a rich interdisciplinary cancer prevention and control knowledge base upon which NCI and its partners will lead the nation in reducing the burden of cancer.

John E. Niederhuber, MD
Director
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Overview

Introduction

In 2006, Dr. Elias Zerhouni, Director of the National Institutes of Health, stated that: "In 20 years we're going to have what I call the 'three P's medicines: predictive, personalized, and preemptive. That's my vision." To achieve this vision, advances in cancer communication must parallel those advances being made in genomics and medicine to make sure the population fully benefits from that progress.

In 2003, the National Cancer Institute (NCI) funded the Centers of Excellence in Cancer Communication Research (CECCR) as a means for harnessing the power of the information revolution to extend the reach, improve the effectiveness, and increase the efficiency of cancer communication. The CECCR initiative was developed as a priority after NCI planners identified cancer communication as an "extraordinary opportunity" for research in the area of cancer control. The innovation and scope of the initiative reflects the enormous potential of cancer communication to improve health. It reflects NCI's recognition that effective communication can and should be used to narrow the gap between discovery and application across the cancer continuum and help eliminate cancer disparities among our citizens.

Cancer communication plays a central role across the entire cancer continuum: encouraging prevention of smoking and other risky behaviors; promoting mammography and other early detection behaviors; improving patients' abilities to participate in treatment decisions; stimulating participation in clinical trials; and working with patients and their family caregivers as they deal with the course of disease and survival.

Emerging communication and information technologies will increasingly permit preventive and screening interventions, health care delivery, and patient and family support to be tailored to the specific needs risk profile and interests of the individual. It should not be that one will interact with far more sophisticated technology when purchasing a book online than when searching for information about breast cancer, or in seeking help to quit smoking, or when monitoring the status of a cancer patient. Just as we seek to eliminate cancer disparities – there should be no disparity between the use and availability of technology in the cancer continuum.

The urgency of harnessing the power of the information revolution to improve the reach and effectiveness of cancer communication is clear. The Science Panel on Interactive Communication and Health, convened by the Department of Health and Human Services (HHS), concluded that few other health-related interventions had the potential of interactive health communications to improve health outcomes, decrease health care costs, and enhance customer satisfaction. Both the Secretary of HHS and the President of the United States have challenged health care leaders to exploit the capacity of health information technology to improve quality of care for all Americans.

There is evidence that advances in communication technologies may be outstripping our capacity to use the technologies for improving population health.

The U.S. Department of Commerce cautioned that a "digital divide" exists that, if not addressed, will create a worsening of concerns over health disparities in the population.

The Institute of Medicine (IOM) warned that an explosion of medical information has escalated so dramatically that unless efforts are made to harness access to that information, the resulting glut is likely to create significant damage within the health care system.

The CECCR initiative is funded by the NCI's Division of Cancer Control and Population Sciences, directed by Robert Croyle, PhD. It is administered by staff within the Health Communication and Informatics Research Branch directed by Bradford Hesse, PhD. Four Centers were funded in 2003, each with its own distinctive contribution to the transdisciplinary field of cancer communication. Recipients of the 2003 awards include the University of Michigan, University of Pennsylvania, Saint Louis University, and the University of Wisconsin.

The report begins with a description of the NCI's rationale for funding the CECCR, then focuses on what each of the CECCRs are now accomplishing, with a review of progress made after 3 years. The latter part of the report offers individual synopses of cancer communication research underway within each of the four Centers. The synopses highlight the distinctive nature of the four in terms of the cancer challenges being addressed, the innovative solutions and research questions being explored, the wide range of methodologies being employed, and the constellation of research disciplines needed to solve the problem.

Section I:

NCI's Rationale for the Centers of Excellence in Cancer Communication Research

There has been an extraordinary transformation in the nature, availability, and use of information and communication technology generally and as applied to health. These ongoing and dynamic changes provide opportunities to accelerate progress in alleviating the national burden from cancer.

As described in the 2005 volume of *Nature Reviews: Cancer,* the turn of the millennium was marked with an extraordinary proliferation of communication technologies–from diffusion of the Internet to advances in cellular telephones and satellite television–that is dramatically increasing the ability of public health planners to accelerate population gains in cancer control and prevention.[1]

■ The Pew Foundation reported that 73% of all adults claimed to use the Internet as of April 2006.[2]

■ Among adult Internet users, 79% said they had looked for health information at some time, with 66% reporting investigation of a specific disease or medical problem.[3]

■ Five percent reported "going to a web site that provides information or support for a specific medical condition or personal situation" on a daily basis.[4]

■ In a study of health communication on the Internet, the term "cancer" showed up as the third most popular health term searched.[5]

■ When asked where they would likely go first for information about cancer, 49% of respondents suggested that they would likely go to their physicians with 33% going to the Internet. Of those who had actually searched for cancer information, 48% went to the Internet first, while only 11% went to their doctors.[6]

■ There is still a great deal of information about cancer prevention and screening obtained through routine use of mass media. In a national sample of 40- to 70-year-olds, 46% had gotten information about colonoscopy, 29% of men had gotten information about PSA, and 64% of women had gotten information about mammography in the previous year from broadcast or print media.[7]

■ *73% of all adults claim to use the Internet.*

■ *79% of the adult Internet users have looked for health information online.*

■ *"Cancer" is the third most popular health term searched.*

As advances in consumer technologies are proliferating, there has been a parallel improvement in biomedical information technologies. These have provided online access to an ongoing explosion in scientific data. In 2004, the National Library of Medicine estimated that it was cataloguing approximately 10,000 new biomedical publications through its online bibliographic retrieval systems each year.[8]

Projections are that the advances in medical information delivery systems will create a wholly new health care environment, one moving toward personalized, preemptive, and predictive medicine.[9]

The information revolution fueling the ongoing change in medical information delivery is fueling a change in public health communication. Mass media campaigns have been a mainstay tool in the dissemination of health messages to the public.[10] Since the onset of the information revolution, traditional mass media have been diversifying, with new specialized markets emerging for television, newspapers, radio, magazines, and the Internet.[11] Now messages can be directed to groups identified by sociodemographic identities, by behavioral stages, or by other self-identified interests.

From the perspective of health promotion, the change holds a promise–largely untested–to improve efficiencies for reaching targeted groups in more culturally effective ways.[12]

Despite this massive change in the communication environment and its application to health, the capacities already existing and newly available are not being fully exploited to better the lives of the population. Some public communication campaigns that focused on cancer behaviors were successful, but others did not affect behavior at all.[13,14] Attempts to use interactive communication technology to tailor communication efforts faced inconsistent success.[15,16] People who brought information to their doctors from direct-to-consumer ads or from the Internet may sometimes bring helpful information and unhelpful information.[17,18] Cancer patients and their families had access to medical information and support groups through interactive media but did not always find that it met their needs, or complemented the limited support their physicians could offer.[19]

The Internet put an enormous amount of highly technical medical information at the fingertips of anyone with access to a search engine. A content review of 25 health web sites offering content related to health in Spanish and English found that 86% of Spanish web sites and all of the English web sites required a high school or greater reading level to understand them.[20] There was important and successful work in each of these areas of cancer communication, but there was much to be learned about how to disseminate the information more successfully and on a scale that would affect the nation's cancer burden.

NCI responds with its own program in cancer communication research.

These changes in the communication environment overall and the recognition of the importance of health communication in particular led to identifying cancer communication as one of the "extraordinary opportunities for research" in NCI's bypass budget proposal to the White House and Congress. It also led to the foundation of the Health Communication and Informatics Research Branch (HCIRB) that houses the CECCRs initiative, within the Behavioral Research Program (BRP) of the Division of Cancer Control and Population Sciences (DCCPS).[21]

The framework for programmatic activities within the DCCPS includes epidemiology, population monitoring, and intervention and evaluation research using experimental, quasi-experimental, and observational methods. By 2001, a portfolio of exploratory R03 and R21 research grants had complemented the portfolio of traditional R01 grants as the branch's basic investment in fundamental research. A burgeoning portfolio of Small Business Innovation Research (SBIR) and Small Business Technology Transfer (STTR)

grants was creating a host of multimedia applications for testing under the umbrella of intervention research.

In response to recommendations from a national conference of risk communication scholars, the branch launched the Health Information National Trends Survey (HINTS) in 2001. HINTS is a surveillance vehicle for cancer control researchers.

Fielded as a nationally representative telephone survey of adults 18 years old and older in the general population, with an oversample of minority populations, HINTS collects data biennially on the use of health information in the rapidly changing communication environment. It collects self-report data on respondents' awareness of cancer control behavior, knowledge of cancer as preemptive disease, and adherence to recommendations for health behaviors, especially in primary and secondary prevention.

The survey, entering development for its third administration in 2007, has provided valuable insights into where deficits in cancer-related knowledge within the general population may lie.

Projections are that the advances in medical information delivery systems will create a wholly new health care environment, one moving toward personalized, preemptive, and predictive medicine.

NCI introduces a core initiative to accelerate cancer communication research and develop new investigators in cancer communication.

Communication and health informatics operate in the gaps between bench and bedside, between discovery in the basic biomedical sciences and delivery through clinical application.

A platform was needed to simultaneously connect activities in fundamental research, intervention research, and program delivery funded with specific research projects and the surveillance platform in health information (Figure 1).

Following on the success of the Tobacco Use Research Centers (TTURC) program, the P-50 Centers Grants mechanism was selected for the CECCRs. The purpose was to identify areas of discovery that take full advantage of the transformational changes enabled by the communications revolution. The areas of discovery would be inherently interdisciplinary with new knowledge sought in areas of cancer communication theory, translational medicine, consumer informatics, behavioral intervention, cultural translation, and patient-centered computing and statistical methodology. The Centers were envisioned as playing a central role in the training of creative cancer communication scientists.

Figure 1. Cancer Control Framework

Centers of Excellence in Cancer Communication Research (CECCRs)

Fundamental Research

Intervention Research

Application & Program Delivery

Knowledge Synthesis

Surveillance Research (HINTS)
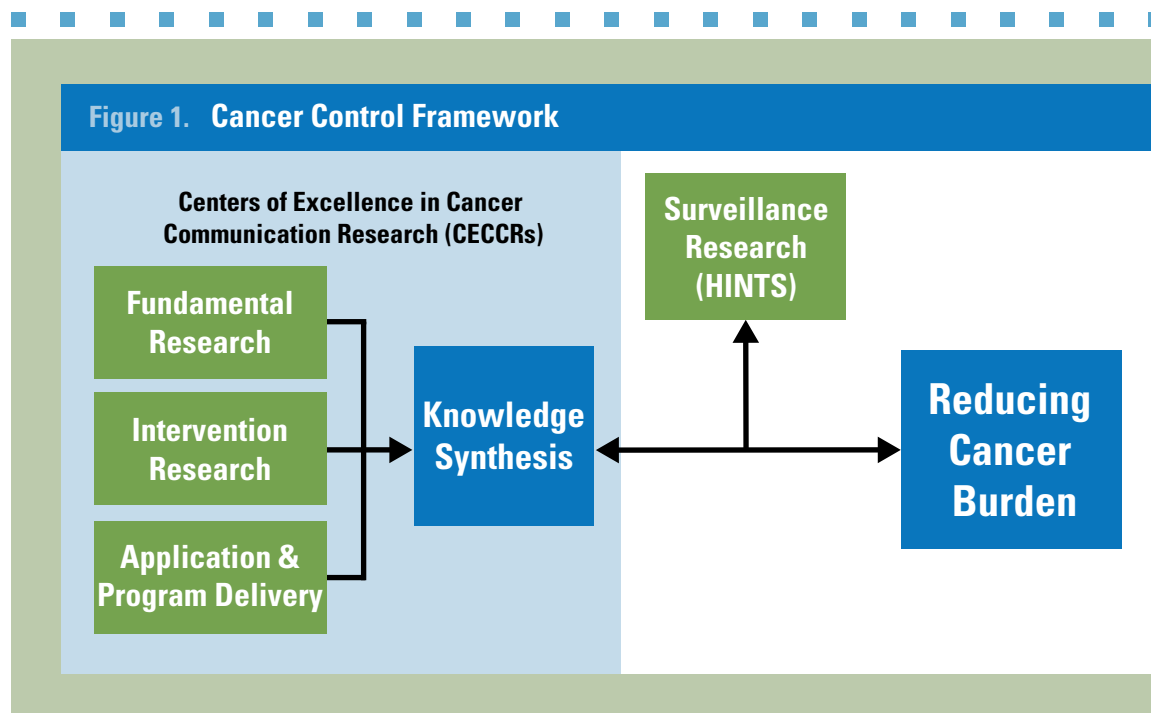
Reducing Cancer Burden

Figure 1. Cancer Control Framework (Hiatt & Rimer, 1999) applied to Health Communication and Informatics; CECCRS represents a connective investment in fundamental, intervention, and delivery research with ties to the Health Information National Trends Survey for surveillance.

The CECCR initiative request for applications laid out specific goals focusing in two areas: interdisciplinary research on cancer communication and development and engagement of new investigators, through both training and attracting established investigators to the field.

Three specific goals were established for the Centers of Excellence initiative:

Goal
Develop cancer communication science.

- Generate basic research evidence to improve understanding of the processes underlying effective cancer communication.

- Support novel interdisciplinary research to inform medical and public health practitioners about how best to communicate to the public, patients, and cancer survivors.

- Increase the number of peer-reviewed publications in the area of cancer communication systems and processes.

Goal
Develop effective interventions.

- Produce evidence-based communication interventions that can be used to modify cancer risk behaviors and improve informed decisionmaking and quality of life.

- Increase the number of evidence-based interventions in understudied areas (e.g., diagnosis, treatment, survivorship and end-of-life, and on understudied populations).

Goal
Train and attract established investigators.

- Increase the number of investigators from relevant disciplines who focus on the study of cancer communication as part of interdisciplinary teams.

- Train interdisciplinary investigators capable of conducting cutting-edge communications research relevant to the context of cancer prevention, detection, treatment, control, or survivorship.

These same goals are used to evaluate the progress of the CECCRs. In subsequent sections of this briefing, both narrative and quantitative information are presented to assess how well the initiative is meeting these goals. To put these goals and the progress being made toward them in context, we first describe the place of the Centers of Excellence within NCI's mission.

The cancer burden reflects not only physician and medical institution quality and the availability of medications and medical technology but also individual decisions and behavior around cancer prevention and screening, and the care and support of patients. Those actions are affected by people's communication with professional and lay networks and their interactions with communication technology.

The potential for reductions for cancers related to behavioral choices is reinforced by "projections that 50% to 75% of the existing cancers could be eliminated by changes in lifestyle alone."

Surveillance statistics reveal a steady decline in age-adjusted mortality rates due to cancer since 1990. The declines are most pronounced for cancers where the individual's behavior is central and where public (health) communication and social marketing campaigns were common. Surveillance data show significant reductions in mortality rates from lung and bronchus cancer in men, cervical and breast cancers in women, and colorectal cancer throughout the population.[22] The potential for reductions for cancers related to behavioral choices is reinforced by "projections that 50% to 75% of the existing cancers could be eliminated by changes in lifestyle alone."[23,24,25]

NCI's 2006 strategic plan[26] recognizes that there are important shortfalls with regard to prevention, screening, and post-diagnosis behaviors within the U.S. population:

- Twenty-one percent of the population still smokes.

- Sixty-seven percent do not engage in exercise at recommended levels.

- Thirty-one percent are obese.

- Seventy percent of women get mammograms every 1 to 2 years, but only 43% are up to date on being screened for colon cancer.

- Even after diagnosis, patients may not learn about the full range of treatments to consider; and they may not comply with the treatment regimens recommended by their physicians. As they live with cancer, they may not make behavioral changes that reduce the likelihood of recurrence, and they may not take all the steps that can reduce the emotional and physical consequences of their cancer and its treatment.[27,28]

- Two to 5 percent of all newly diagnosed adult cancer patients participate in clinical trials.[29]

- Fifty-two percent of pediatric bone marrow transplantation patients evidenced significant adherence problems with recommended procedures, particularly use of oral antibiotics.[30]

- Over 47% of breast cancer patients missed some of their chemotherapy doses.[31]

All of these examples reflect individual behavior. Part of the burden of disease and suffering from cancer is a consequence of individual decisions and behavior across the cancer continuum, from prevention through early detection, diagnosis, treatment, and survivorship. In turn, those decisions and behaviors may have a variety of causes: environmental constraints making ideal decisions impossible, or poor individual judgment despite full information.

Behavior may also result from health and media systems that leave individuals ill-informed. People deciding whether to adopt prevention and screening behaviors may have been left with inadequate knowledge, beliefs, attitudes, skills, and perceptions. Cancer patients and their families may be left without adequate sources of information and personal support to underpin decisions that affect their survival and their quality of life. Communication interventions have the potential to address these issues of inadequate information and support for decisions on a large scale and save lives in the future.

Communication interventions have the potential to address these issues of inadequate information and support for decisions on a large scale and save lives in the future. Effective communication programs can provide the wide diffusion of important information based on research with the population. Others will supplement one-way diffusion with interactive media – the opportunity for individuals to engage in two-way communication to get their questions and concerns answered, and to obtain the sort of social support they may need. In the discussion that follows, references to information and communication technology embrace broad definitions of both.

Communication interventions have the potential to address these issues of inadequate information and support for decisions on a large scale and save lives in the future.

The CECCR initiative recognizes that currently, the diffusion of accurate cancer-related information is inadequate. The communication system to support patients and their families is highly variable. The health care system may not reach much of the population when people need to make prevention and screening decisions; scarce resources may undermine the medical system's capacity to reach cancer patients and survivors as often as required and with the range of information and emotional support required. Depending on the health care system to address this communication problem can be unrealistic. Mass media and the Internet reach wide audiences, but they can provide too little information, too much undigested information, or information ill-adjusted to individual needs. Inadequate information makes informed decision making difficult, and inadequate skills may make effective implementation of decisions once they are made unrealized.

The burden of disease and suffering, in part reflecting institutional factors and social determinants, is unequally distributed across the population. This need to address unequal burdens creates a particularly difficult challenge for building effective communication systems.

There is good evidence that effective and efficient communication systems can be built and can affect behavior. We can do a better job in exploiting communication technologies to improve communication and improve healthy behaviors, reducing cancer morbidity and mortality. Building evidence-based communication systems to support cancer-related decisions, without imposing unrealistic additional burdens on the medical system, is an urgent task, and one directly addressed by the CECCRs.

Is more cancer communication research really necessary even if cancer communication may be essential? The CECCR initiative recognizes that cancer communication is quite different than communication work in commercial and other realms, and requires investment in both specific intervention research and in underlying science.

Although many have long recognized the important role of communication in reducing the cancer burden, NCI's leadership role in supporting cancer communication science is a more recent development. There may be a sense that one should be able to rely on the entire industry of journalists, public relations experts, advertisers, and patient support professionals who are already involved in communication. In fact, the core assumption of the CECCR initiative is that cancer communication is very much in need of a science base, a foundation in theory, rigorous empirical work, and peer review.

Public health communication initiatives, including those addressing cancer, face a very different set of problems than commercial communication campaigns. There is the issue of magnitude of expected effects. Commercial advertisers are quite happy if they can gain 1% to 2% in market share over a long period. A cancer communication campaign (e.g., addressing colon cancer screening) expects far larger and quicker increases in behavior.

An important issue is what behavior or product is being diffused. Advertisers sell products that provide immediate, tangible rewards: a sip of Coca Cola® or a puff from a cigarette. They may address choices that have little consequence, such as choosing one toothpaste over another. Cancer communicators encourage behaviors that are often immediately unpleasant (stopping smoking or having a colonoscopy) and that may or may not result in an immediate and tangible benefit. Prevention programs may promise only that something is less likely to happen at a future time. Communication programs can also be required to address quite complex behaviors –like providing support for survivors.

There is the issue of resources. Commercial communicators have substantial financial resources to support a narrowly focused objective. For example, Coca Cola invested $3.7 *billion* into advertising in 2005.[32] Cancer communicators have to make do with much lower levels of resources (e.g., the Centers for Disease Control and Prevention [CDC] budget for skin cancer prevention, including the "choose your cover" sun protective behavior campaign was $2 *million* annually) and, thus, must use these funds more efficiently.

Cancer communication research is required because the path to success is often uncertain. The experience in both commercial and cancer communication realms is mixed.

In the commercial world, most product advertising campaigns do not succeed in winning additional market share. Almost every product on the market is supported by advertising, yet there are still winners and losers. In cancer and public health communication, the picture is also quite mixed. The literature on communication campaigns suggests that the average campaign has some success but includes many examples of no change.[33] For example, in recent years there are a number of studies showing success for youth anti-tobacco campaigns,[34] including the national Truth campaign.[35] On the other hand, there is no evidence that the billion dollar National Youth Anti-Drug Media Campaign was successful, and some evidence suggests that it actually boomeranged, increasing youth interest in marijuana use.

There can be no assumption that a communication effort will succeed. Anything that increases the likelihood of success, including a careful research basis, is clearly needed. Indeed, advertising and public relations professionals work with a research base. They mesh a range of research (albeit largely unpublished research) with their campaigns and make use of a well-established system of tracking outcomes: product sales.

It is not just cancer communication research that is required, it is cancer communication science. It is important to do research for specific interventions; it is equally important to develop science that allows generalization beyond a single intervention.

The argument for a stronger science base for cancer communication is two-fold. Research is an important *element of any intervention*. Formative research about audiences, about

the influences on their behavior, about the effectiveness of individual messages, and summative research about the effects of full-blown interventions help make a specific effort more successful. The science base is important in a larger sense.

Research about *principles of communication* that generalize across cancer communication interventions can provide guidance to interventions that cannot afford to do all possible research on their own:

- Research about how cancer patients vary in their reliance on different communication sources to make decisions;

- Research about how strong and weak arguments and more or less intense formatting in anti-tobacco advertising messages affects ad persuasiveness;

- Research about how different ethnic groups respond to narrative versus didactic content in pro-mammography messages;

- Research about alternative approaches to tailoring messages about smoking cessation in an efficient way; and

- Research about how to provide emotional support to patients and families as they cope with critical cancer decisions.

All of these topics (among the many studied by the CECCRs) are relevant to specific interventions—they are studies in the broader science of cancer communication. They provide generalizable knowledge that comes from sustained, systematic, and rigorous research programs that undergo peer review.

What is already known about best practices in doing cancer communication is not fully utilized by today's medical and public health systems. Yet, there is still a great deal to learn about how to do effective cancer communication.

Section II:

What Are the Centers of Excellence in Cancer Communication Research Accomplishing?

It is clear what NCI wanted to achieve with the CECCR initiative. Are they on a path to accomplishing those goals?

The CECCRs are structured like many center grants as specified by grant guidelines. Each site focuses on a main theme with three or more individual, hypothesis-driven research projects tied to that theme. Each site has a pilot or developmental research project process and a plan for career development/training of new researchers in the field of cancer communication. Each site includes a number of core resources essential for supporting large-scale interdisciplinary research for example, biostatistics, the advancement of new theories and methodologies in cancer communication research, message design, and technological analysis.

CECCRs' main research themes and primary projects	
University of Michigan	***Develop an efficient, theory-driven model for generating tailored health behavior interventions that are generalizable across health behaviors and socio-demographic populations.*** • Project Quit – Studying the Active Components of Smoking Interventions • Eat for Life – Cultural and Motivational Dietary Message Tailoring • Guide to Decide – Risk Communication: A Tamoxifen Prophylaxis Decision Aid
University of Pennsylvania	***Understand how best to work with the complex public information environment to affect the behavioral choices people make relevant to cancer prevention, screening and post-diagnosis treatment and survival.*** • The Cancer Information Seeking and Scanning Behavior Project • Biobehavioral Evaluation of Anti-tobacco Public Service Announcements • Communicating Genetic Risk in the Media: Effects on Efficacy and Healthy Behavior
Saint Louis University	***Enhance the reach and relevance of cancer communication among African Americans.*** • Cultural Tailoring for Cancer Prevention and Control in African American Women • Using Computer Kiosks for Breast Cancer Education in Six Community Settings • Using Survivor Stories to Enhance the Effectiveness of Breast Cancer Communication
University of Wisconsin	***Help people affected by cancer use new communication technology, reduce their suffering, and enhance psychological well-being.*** • Understanding How Interactive Cancer Communication Systems Work and for Whom • Building Continuity in Care – Supporting the Facing Advanced Cancer, Their Family Caregiver, and Clinical Team • Improving the Timing and Value of Information and Support for Cancer Patients Over the Course of the Disease

This section focuses on the CECCR's goals related to communication science and developing interventions and summarizes how the Centers responded to them.

The CECCRs address the three major challenges of cancer communication: reach, effectiveness, and efficiency. Communication systems must reach and engage large populations with effective messages in a cost-effective way.

The CECCRs are dedicated to reducing the cancer burden in the United States through increasing the *reach, effectiveness*, and *efficiency* of *communication* pertinent to cancer prevention, decisionmaking in diagnosis and treatment, and the quality of life for survivors.

Reach

Information pertinent to cancer that fails to reach the target population cannot possibly affect cancer prevention, decisionmaking in diagnosis and treatment, participation in clinical trials, or the quality of life for survivors. Maximizing the reach of cancer information, making it available to larger and underserved populations is a minimal requirement for an effective large-scale cancer communication program.

Populations subject to a disproportionate burden of cancer death and suffering often have less access to health information. The CECCRs are advancing the reach of cancer communications to underserved populations, exploring the role of new technologies as means for delivery of cancer communications,

and describing the channels that cancer populations and others use for acquiring information about cancer and its prevention. Together these lines of research advance what is known and what is possible to achieve in extending the reach of cancer-relevant information to the public.

- One of Penn's projects involves a national prospective survey of 2,400 40- to 70-year-olds, investigating what information sources (medical, mediated, interpersonal) they use in making specific decisions about cancer prevention and screening. Knowing what communication sources they use, and whether they are influential in subsequent decisions, will allow better planning for campaigns.

- Saint Louis carried out a random digital survey of 850 African American readers of Black newspapers in 24 cities to understand what cancer-relevant information they are getting, from which sources, and how it is associated with perceived importance of cancer and preventive actions.

- Wisconsin translated its breast cancer interactive cancer communication system (shown in randomized control trials to improve quality of life) into the Spanish language, which provided universal access to Latino women and their families and promoted the site with a national media campaign.

- Each of Michigan's projects work with the integrated health care systems of the NCI's Cancer Research Network (CRN). Over 50% of Americans and over 60% of Medicaid recipients are enrolled in integrated health care organizations.

Effectiveness

Communication content can reach the target population, but reach is not enough. It must be effective. Messages must contain both adequate content and form to change behavior, improve decisionmaking, or enhance the quality of life.

The CECCRs are dedicated to studying which forms for communicating information about cancer are most effective given the target audience and desired outcome. These messages must contain arguments that persuade or are usable, in forms that make the content interesting, accessible, and credible. They must appeal to diverse audiences that bring different experience and cultural understandings. They are concerned with how to present socially supportive information and perspectives for an optimal quality of life for those who have cancer.

The Centers of Excellence are dedicated to understanding and designing cancer-relevant communications that are effective across the entire spectrum of issues relating to cancer.

- Michigan found that a smoking cessation intervention was particularly effective when it tailored its messages on four characteristics of individuals, including highly-tailored testimonials of similar smokers, expectations of positive outcomes that occur through quitting smoking, skills relevant to the individual's quitting barriers, and a more personal source of the smoking cessation information.

- Saint Louis found negatively framed disparity communication (e.g., "Blacks are doing worse than Whites") – commonplace among many physicians, health care organizations, researchers, and especially news media – actually undermines efforts to reduce cancer disparities, especially among African Americans who mistrust the science and medical communities.

- Penn has evidence that anti-smoking advertisements that show smoking but do not provide strong verbal arguments for quitting smoking, actually increase viewers' physical craving for cigarettes.

- Wisconsin has developed a decision aid to help individuals understand what respite care is, its importance for both the patient and caregiver, and how to put their decision into action by implementing respite care.

Communication content can reach the target population, but reach is not enough. It must be effective. Messages must contain both adequate content and form to change behavior, improve decisionmaking, or enhance the quality of life.

Efficiency

Even when information reaches its target audience in an effective form, the communication intervention needs to be efficient and provide maximum impact at the lowest cost. While the most effective intervention program might be to design for each person a personally delivered, unique diet of information for prevention, testing, diagnosis, treatment, and survivorship, such a program is cost prohibitive and is likely to preserve the disparities that already exist between the information-rich and information-poor.

The Centers of Excellence are exploring delivery systems for cancer information that are efficient even in today's highly segmented, competitive media environments. New technologies can deliver personally tailored information to assist in prevention, and decision-making about diagnosis and survivorship.

Understanding the most efficient means of reaching the public with effective information ensures that even small effects will translate into substantial, cost-efficient gains for the entire population.

Understanding which outlets for cancer information that people use – both people not at immediate risk and those at serious risk – allows placing targeted campaigns in the most efficient channels. Understanding the most efficient means of reaching the public with effective information ensures that even small effects will translate into substantial, cost-efficient gains for the entire population.

In Saint Louis, research has shown that the use of interactive touch-screen computer kiosks providing tailored breast cancer and mammography information is significantly higher in laundromats than in beauty salons, churches, health centers, social service agencies, and public libraries. Based on their lower rates of screening and lower breast cancer knowledge scores, kiosk users in laundromats have a greater need for breast cancer information than users in other venues. Given limited resources, putting kiosks in laundromats will reach more women than other community settings.

The Wisconsin Digital Divide project studied the costs of delivering a proven cancer communication system to underserved, low-income women with breast cancer in Detroit and rural Wisconsin, the majority of whom had no access to computers. The findings included a demonstration of substantial/lasting improvement in quality of life at a cost of $300 to provide computers, Internet access, and training to these women. This is less than it costs for 3 months' supply of anti-depression medication.

The CECCR's work on these problems involve some large and a substantial number of small studies, and an increasing number of publications. Twelve major research projects are in process, with major results expected over the next 2 years.

Some studies and early results are presented in the next section of the report where the individual Centers outline their programs and illustrate their research. CECCR-supported research has led to applications for new grants from the National Institutes of Health (NIH) and other sources.

In Table 1, the number of discrete studies undertaken at each site in addition to the primary projects is presented, along with the number of publications reflecting research fully or partially supported by the Centers and already published or in press, along with the number of small and large grants received and linked to the CECCRs as of September 1, 2006. All of the individual projects and publications are listed in the appendix

The Centers of Excellence are committed to develop and test theory relevant to the construction of cancer communication interventions. They are committed to the use of a wide range of research designs and innovative measures appropriate to the research questions.

All of the CECCRs make use of established theoretical approaches and actively develop and test theory in their research. The theory base includes behavior change theory, communication theory (including both message theory and exposure theory), social marketing theory, ideas about cultural competence, and forces likely to reduce disparities.

Table 1. CECCR productivity					
Centers of Excellence	Papers published or in press	Presentations*	Large grants received	Small** grants received	Small projects in the field
University of Michigan	28	114	11	4	8
University of Pennsylvania	25	41	7	7	22
Saint Louis University	49	70	22	8	8
University of Wisconsin	54	54	14	33	25
Total	**156**	**279**	**54**	**52**	**56**

* Presentations made at national or international scientific meetings.
** Small grants are those with under $100,000 in direct costs.

Center teams use theory to construct interventions and messages, taking advantage of theoretical mechanisms of informed decisionmaking and persuasion. They develop and test theory to understand what makes one message more effective than another. This work fits with the focus on identifying generalizable principles for effective cancer communication described in the previous section about the role of communication science.

- Wisconsin has an internal working group addressing alternative theories that may explain acceptance, use, and effects of the Comprehensive Health Enhancement Support System.

- Penn has been working on differentiating cancer-relevant prevention and screening behaviors for their likelihood of being influenced by different types of normative pressure. For example, they find that intention to eat fruits and vegetables is substantially related to the perceptions that eating fruits and vegetables is common, but intentions to get screened (whether mammograms, PSAs or colonoscopy) are much more related to the belief that others expect one to get screened.

- Saint Louis led a national and interdisciplinary working group of 12 scientists (including representatives from the Penn and Wisconsin Centers of Excellence) in developing a new typology of narrative communication effects across the cancer control continuum (*Annals of Behavioral Medicine*, in press).

- Michigan is identifying distinct ethnic identities within the African American population, then testing cancer prevention messages specifically tailored to these identities.

All the CECCRs apply state-of-the-science study designs. In some cases the Centers use individually or community randomized controlled trials to test the effects of message and dissemination strategies, comparing different strategies against each other and against "best standard of care" control groups. In other cases they use quasi-experimental designs or entirely observational designs, balancing the need for strong inference with the need to fully represent the natural environment. In each case the designs fit the research questions addressed.

All the Centers develop and validate innovative measurement strategies to assess critical theory-based mediating and outcome variables. These strategies include content analysis, assessing message exposure through surveys, using online measurement technologies, analysis using geographic information systems, and experimenting with physiological measurement of outcomes.

A primary NCI goal for the CECCR initiative is to attract and train new investigators with some emphasis on interdisciplinary work. The goals include increasing the number of investigators from relevant disciplines who focus on the study of cancer communications as part of interdisciplinary teams, and training interdisciplinary investigators capable of conducting cutting-edge communications research relevant to the context of cancer prevention, detection, treatment, control, or survivorship.

Each Center of Excellence, and almost every project in each Center, calls on the skills of people from a wide range of disciplines.

Each Center of Excellence includes individuals from a variety of disciplines who serve as leaders of individual major projects and cores. Of more importance, nearly all of the projects themselves are collaborations among individuals from different disciplines. In part, this is captured by the list of primary disciplines represented by the post-doctoral staff at each CECCR in Table 2. Even when specific projects did not involve individuals with different primary disciplines, the projects themselves invariably relied on the theories and methods of multiple disciplines.

Table 2. Primary disciplines represented by post-doctoral staff	Michigan	Penn	Saint Louis	Wisconsin
Communication research	■	■	■	■
Public health education/behavior	■	■	■	■
Social and cognitive psychology	■	■	■	■
Clinical/community/health psychology	■	■	■	■
Developmental/educational psychology		■	■	
Journalism/media relations			■	■
Oncology	■	■		■
Health services research	■	■	■	■
Other medical specialists	■	■	■	■
Genetics		■		
Statistics/epidemiology	■	■	■	■
Engineering				■
Environmental health			■	■
Sociology/anthropology	■	■		■
Marketing research/management		■		
Nursing		■	■	
Computer science	■			■
Education	■		■	■

This listing of disciplines does not fully describe the interplay among the individuals who bring varied disciplinary training to solving particular research problems. Specific examples provide an even richer idea of how this has worked to produce better research.

- One of Penn's projects required the development of a questionnaire designed to assess how cancer patients engage with information sources to make decisions. The instrument was constructed over a 12-month period by a research group that included four communication researchers, a public health researcher, a clinical psychologist, a social psychologist, two oncologists, and two physician health service researchers.

- At Saint Louis, an anthropologist and behavioral scientist recognized the cultural importance of storytelling and experience-based knowledge among many African American women, and worked with communication and persuasion researchers to identify active ingredients of breast cancer survivors' stories so they could be used more effectively to promote mammography in unscreened women.

- Having found that more deeply tailored testimonials of successful quitting leads to higher abstinence, Michigan is working with a Hollywood Screenwriter Guild member to develop stronger tailored smoking cessation narratives. Neural activity as a result of these tailored materials is being tested in collaboration with researchers from psychiatry, cognitive psychology, and physics.

- Wisconsin's effort to develop a theory driven approach to the development of interactive cancer communication systems was enhanced by the perspectives of different disciplines. For instance, theorists from clinical psychology introduced the Center to self-determination theory, systems engineers introduced them to theories of organizational change and quality improvement. A probabilistic model that harnesses artificial intelligence accurately predicts breast cancer risk by combining imaging findings with demographic information. These were merged to advance Wisconsin's theory base.

The interdisciplinary character of the CECCRs' work depends on collaboration with other institutions as well as those from different disciplines.

Communication as a field must be linked to other fields; institutions that work on communication must complement other institutions that work on topic-specific concerns and on implementing of communication research results. NCI recognizes that effective communication can and should be used to narrow the enormous gap between discovery and the application of discoveries. Failure to recruit patients for clinical trials slows the pace of medical progress. Communication interventions have a role to play, particularly in recruiting diverse populations. Clinicians are charged with helping their patients make informed decisions about treatment choices, or post-diagnosis quality of life issues. Can their success be improved by use of communication technology?

For communication work to be productive in cancer prevention and control, it must be fully informed by the substantive work in critical areas of cancer prevention such as tobacco cessation, screening programs, cancer survivorship, and in many other areas. It should be linked to organizations that are at the forefront of patient care and outreach. Cancer communication science work must be associated with cancer communication practice.

Each CECCR has built these kinds of links and interdisciplinary relationships. Centers work collaboratively with other institutions in their own or neighboring universities that focus on cancer (NCI-designated Comprehensive Cancer Centers, TTURCs, NCI-funded health disparities centers), with agencies that implement health care and communication programs in the field (American Legacy Foundation, African American newspapers, HMO-Kaiser Permanente, Group Health Cooperative in Seattle, Henry Ford Health System in Detroit), and sometimes with community advisory organizations (Saint Louis University Board of Community Partners). There have been ongoing links and collaborations with NCI and other programs that do related work (Office of Cancer Communication and Cancer Information Service, HINTS survey group, Office of Education and Special Initiatives and NCI/CDC Cancer Prevention and Control Research Network, National Institute of Diabetes, Digestive and Kidney Disorders).

Several of these groups have attended semi-annual CECCR grantee meetings. The P-50 platform has opened a pipeline between the NCI and other cancer-control partners. The CDC, for example, has funded a similar set of centers to work on problems outside the scope of chronic disease. The principal investigators from the two sets of initiatives have begun to work together and have served as contact points for HHS activities in health communication.

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In addition to cross-disciplinary work within the Centers of Excellence and between the Centers and other institutions, the Centers collaborate with one another.

An objective of the CECCR initiative was to create a level of coordination between the Centers that is impractical under individually funded R01 grants, while building pipelines of communication from the newly synergized group of centers to other parts of the cancer-control community. To encourage synergy, two initiative-wide Center grantee meetings occur each year. Scientists share results, present papers, and discuss methodological challenges in a scientific venue focused directly on the issues associated with transdisciplinary communication research.

There are formal cross-Center workgroups. One developed a new typology of effects and mechanisms of effect to better understand and apply tailored cancer communication. A second developed a new model of effects of narrative cancer communication across the cancer control continuum. Two more workgroups are measuring exposure to media and outlining theory concerning how ehealth programs have effects, are in process.

Formal workgroups are expected to produce publishable products, and there are informal collaborations between Center personnel. Michigan survey research expert Mick Couper talked with the Penn team about alternative approaches to implementing their surveys of the general population. Michigan and Saint Louis University are jointly evaluating and improving tailoring software developed at Michigan. Michigan's CECCR worked with Tim Baker at Wisconsin to utilize smoking-related questions from the Wisconsin Transdisciplinary Tobacco Research Center for Project Quit questionnaires. Wisconsin and Saint Louis University are collaborating on participant recruitment for one of the primary studies at Wisconsin. Michigan and Saint Louis have combined their individual collections of African American images for communication production into a single resource. Two Pennsylvania graduate students are using Wisconsin ehealth transcript data to write dissertations about cancer patient support groups. A Wisconsin pre-doctoral fellow completed her thesis research using a Saint Louis University dataset evaluating effects of cultural cancer communication (with Wisconsin and Saint Louis University mentors).

The CECCRs have actively recruited established investigators and provided training to a new generation of cancer communication investigators.

The Centers of Excellence initiative is a major step forward for the field of cancer communication science. Its success will be measured by its research progress and by its ability to bring new individuals to the field, established investigators and new post-doctoral and pre-doctoral (MA and PhD) trainees.

After 3 years, there is already marked success in all the CECCRs in this process. Three sites–Michigan, Saint Louis, and Wisconsin–had prior substantial experience in cancer communication. Penn had less experience in cancer communication. Most of its investigators and students were either new to cancer or new to communication.

Part of the strategy for attracting and training new investigators is providing them the opportunity to initiate discrete projects. This has provided opportunities to pilot new ideas for established investigators.

All of the Centers of Excellence have carried out developmental research programs. Some of these research projects have been closely tied to the major research efforts – testing proposed measures or investigating other methodological elements, or undertaking a parallel study with a new population. Other spin-offs have been linked to those major projects but are testing discrete hypotheses.

Table 3. Number of new cancer communication investigators or trainees during the first 3 years of operation			
CECCR	**New senior and junior faculty investigators**	**Post-doctoral trainees**	**Pre-doctoral trainees**
University of Michigan	17	4	2
University of Pennsylvania	19	10	22
Saint Louis University	11	14	5
University of Wisconsin	6	3	19
Total	**53**	**31**	**48**

There have been pilot projects funded relevant to the overall theme of the Centers but distinct from the major research projects, giving new investigators an opportunity to explore new areas and see if it led to a rich area of (fundable) research. There are dozens of such projects across the CECCRs. The number of projects were listed in Table 2. The comprehensive list of pilot and spin-off projects can be found in the appendix. Some examples include the following:

- Michigan studied the effects of an online weight management program intervention among nonrespondents to the original data collection activity.

- Penn assessed responses to anti-smoking advertisements using fMRI and eye-tracking technologies to see how such covert measures compared to self-report measures.

- Saint Louis used Global Information System (GIS) analyses to determine how far kiosk users traveled from their home to the location where they used the kiosk. Findings showed that kiosk users at laundromats and public libraries were drawn from quite nearby; users at churches and beauty salons had the longest mean travel distance. Findings show how geospatial analysis of health data can be used not only for surveillance purposes but also cancer communication planning.

- Wisconsin completed a study to document the types of assets or strengths that patients bring to their cancer on the assumption that patients would do better if support programs built upon the strengths of the patients. These "assets" are now being incorporated into the development of the interactive cancer communication systems.

Endnotes

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Center of Excellence
in Cancer Communication Research at the

University of Michigan
Center for Health Communication Research

What is the CECCR at the University of Michigan about?

The primary motivation for our Center is the concern that new communications technologies are moving well beyond our understanding of even basic message content, presentation, and delivery principles. To address this concern, the CECCR is employing a systematic, iterative process for discovering optimal population-based health communications tailored to specific characteristics of the individual. This process focuses on potentially active psychosocial and communication factors of health behavior interventions and their interactions with characteristics of the individual.

While the majority of health behavior change interventions tailored to specific needs and interests of the user have demonstrated promising results. (Brug, 1999; Rimer and Glassman, 1999) A number of well-designed trials have failed to find advantages over untailored, one-size-fits-all materials. We believe that a step *backward* must first be taken to systematically screen for and identify the active psychosocial and communication components of computer-tailored health behavior interventions. A more analytic approach to identifying these active elements should quickly lead to rapid advances in cancer communication.

Moreover, we believe that the field's current research strategies are inadequate in harnessing the potential of new communications technologies. By the time findings are disseminated, the technology changes, populations change (e.g., become more sophisticated in their understanding of a communications channel), and the field continues to lag behind. Michigan is, therefore, engaged in a paradigm-changing approach to this dilemma using a sequential experimentation process used extensively in the field of engineering. This approach uses a large number of randomized trials embedded in a fractional factorial design to identify active intervention components, investigate their interrelationships, identify subgroups for whom the component has its greatest impact, and select their settings judiciously to optimize outcomes at an individual subject level. The collaboration generated a description of this approach for behavioral and prevention scientists.

The sequential experimentation process uses two major phases: screening and refining. In the screening phase, active treatment components (i.e., the ones that have the greatest impact) are identified from a large number of potentially important treatment components. Large fractional factorial designs are used in this phase. The underlying philosophy with the use of these designs is that only a small subset of the treatment components and their interactions will be important. The goal of the second phase is to refine our understanding of the effects of the important components that are identified in the screening phase. This phase will lead to a refined set of principles for formulating optimal treatments, and for understanding the effects of the individual components for specific subgroups of users.

Primary research

The University of Michigan CECCR supports three primary research projects, each focusing on a different type of outcome:

- Project 1 aims to facilitate smoking cessation, a behavior to be *subtracted* from one's lifestyle;

- Project 2 focuses on promoting fruit and vegetable intake among African American adults, behaviors to be *added* to one's lifestyle;

- Project 3 is developing a decision aid to help women decide whether to undergo tamoxifen prophylaxis for breast cancer prevention using either raloxifene or tamoxifen, an *informed decision* where no particular behavioral direction is advised.

Each project is using fractional factorial designs to determine the potential active elements of tailoring, including, but not limited to, communication factors such as message content, message framing, message source, and graphical presentation; individual factors such as culture and sociodemographics; and psychological factors such as motivation and self-efficacy.

Moreover, each project is working within at least two integrated health care organizations across the country, a setting in which over half of Americans (including over 60% of Medicaid recipients) receive their health care. Successful, ongoing collaboration with the National Cancer Institute's Cancer Research Network (CRN) of integrated health care organizations has allowed the unique opportunity of testing our interventions in large, highly relevant, generalizable settings.

Integrated health care settings (including health maintenance organizations (HMO) and preferred provider organizations (PPO) offer several advantages to conducting public health research and intervention delivery because of their defined population and provider groups, and because of the integrated nature of their care delivery. The integrated care organizations of the CRN are considered pioneers in a marketplace where HMOs and PPOs often look to other, opinion-leading health systems for direction. In today's competitive health care marketplace, innovative prevention services are (1) effective, (2) reach a large proportion of the population in need, (3) are low cost, and (4) have a high likelihood of adoption. Our collaboration with the CRN opens an avenue to numerous future studies involving more CRN-based researchers and integrated health organizations.

Figure 1. University of Michigan's Center for Health Communication Research (CHCR) and Cancer Research Network
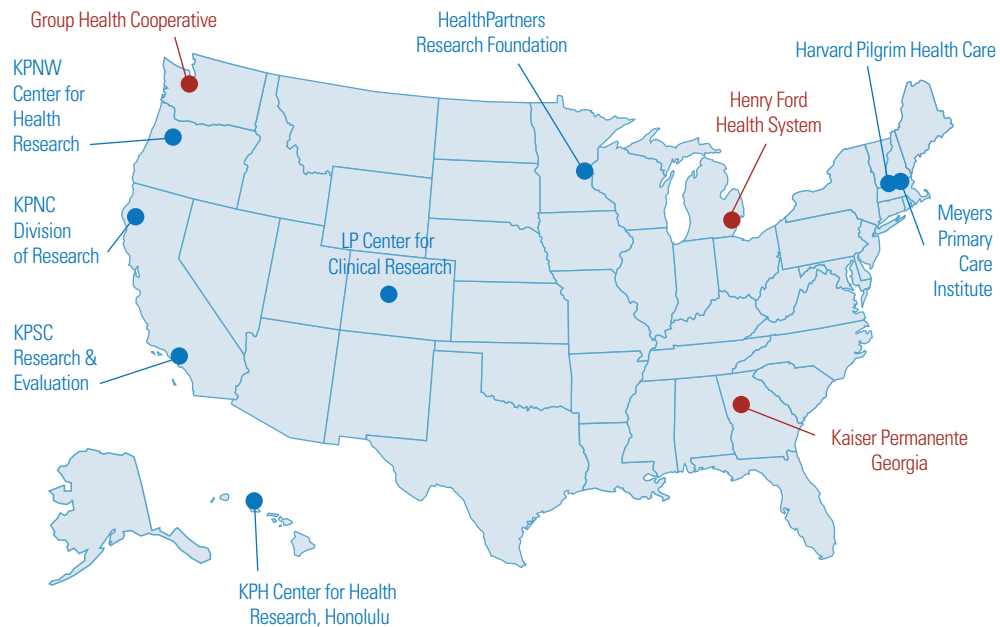
Michigan is currently working with three integrated health systems within the CRN:

Group Health Cooperative (GHC) – the nation's largest consumer-governed, nonprofit health care system. GHC provides coverage and care for 1 in 10 Washingtonians, with total enrollment of nearly 600,000 members.

Henry Ford Health System (HFHS) – the nation's 10th largest HMO and the largest in Michigan. The diverse population served by HFHS includes persons from all socioeconomic levels and reflects the age, race, and sex distribution of the Detroit metropolitan area as well as many other metropolitan U.S. cities.

Kaiser Permanente, Georgia Region (KPG)– located in Atlanta, KPG's over 280,000 members represent regional population diversity–roughly 60% are White and one-third are African American.

Developmental research

A priority within the Michigan CECCR is innovative research that might ultimately lead to large advances in our knowledge of interactive health communications. Because this emerging field is still establishing a foundation of data collection, measurement, and experimental design methods, we are particularly interested in building collaborative research with investigators who specialize in these areas but have not necessarily entered the health communications area. Two such projects include a web-based survey research study with Dr. Mick Couper from the Institute for Social Research and a sequential experimentation design study Dr. Susan Murphy from the Department of Statistics. Another interest is in the connections that can be made with eHealth technologies. Dr. Caroline Richardson is conducting research using pedometers that connect to an Internet-based goal-setting and feedback program created through the Center of Excellence.

Technology transfer

For the past decade our Center has devoted significant resources toward the development of software that enables rapid development of tailored print, Internet, and PDA messages. The CECCR mechanism has allowed us to develop a shareware version of this software for dissemination to research and other non-profit organizations. In the fifth year of our CECCR we will offer a summer workshop in the use of this software along with a workshop related to effective tailoring content.

Core resources

All Michigan CECCR research is supported by a set of core resources in Administration; Biostatistics; Theory and Measurement; Tailoring Technology; and Recruitment and Data Collection. Each core interacts with the projects and other cores, creating both a significant economy of scale and a conceptual and technological synergy unavailable through the sum of individual projects. The Center also places great emphasis on career development opportunities by hosting pre- and post-doctoral fellowships, monthly cancer communication seminars, and a 2-week tailoring training institute.

Primary Project:

Project Quit – Studying the Active Components of Smoking Intervention

Victor J. Strecher, PhD, MPH
Principal Investigator

Problem

While roughly 10 times as many U.S. smokers turn to the World Wide Web (web) than to quitlines for assistance in quitting, very little research has been conducted in this area. As a result, programs of questionable utility continue to dominate the web. Three recent randomized trials have demonstrated the overall efficacy of web-based cessation programs, yet we know almost nothing about the active elements of such programming and have little to recommend web developers of these programs.

Disciplines involved

Behavioral science, statistics, web-based survey research, software engineering, graphic design, instructional design, medical care organization.

What we know

We know that tailored print- and web-based smoking cessation interventions generally result in greater smoking cessation than untailored cessation interventions. Negative results, however, occur from well-designed studies. It is unknown why some studies have demonstrated positive effects and other studies have not.

Research questions

This study intends to research the effects of specific psychosocial and communication factors on smoking cessation in a tailored web-based intervention. The study also investigates how these effects are moderated by relevant characteristics of the individual (e.g., baseline level of motivation and self-efficacy, barriers, need for cognition, health locus of control, and sociodemographics and health status).

Methods

Project Quit uses a multiphased, dynamic, experimental process to screen for and refine active elements of web-based smoking cessation programming among cigarette smoking members of two large HMOs. The project is using a sequential approach for identifying and refining the active factors of tailored health communications. Research using the field's most commonly used experimental designs would take years to assess even a few factors. Instead, using the fractional factorial design allows us to screen the main effects and two-way interactions of large numbers of psychosocial and communications factors simultaneously. This sequential approach is novel in the cancer prevention and control field. Our Phase I results demonstrate the power and efficiencies of this approach.

Figure 1. Number of active factors received (efficacy, outcome, source, testimonial) by 6-month abstinence (7-day point prevalence)

(N=1411; Wald X^2=6.0; p<.01)

31% 29% 33% 35% 44%

6-mo abstinence (7-day pp)

Number of active factors received

Low tailored ←————→ High tailored
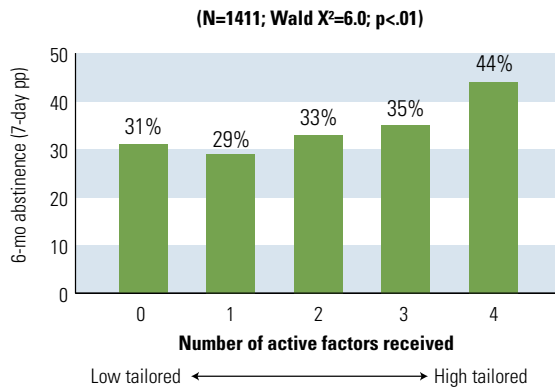
Figure 2. Path analysis of tailoring depth, number of web sections opened, and 6-month abstinence (7-day point prevalence)

.06*

Tailoring depth → # web sections opened → 6-month smoking abstinence

.06** .09***

*   p<.05
**   p<.01
*** p<.001
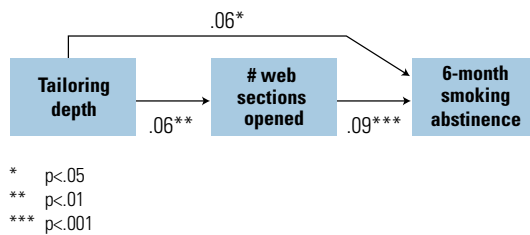
Results

The Phase I (screening) study of 1,845 smokers is now complete. At 6-month follow-up, 1,411 (71%) of the initial sample had been reached. The fractional factorial design trial identified four potentially active factors: outcome expectations, efficacy expectations, testimonials, and message source. Smokers receiving highly tailored versions of each of these active factors had a 44% cessation rate at 6-month follow-up (Figure 1). This is compared to a 31% cessation rate among smokers receiving less-tailored versions of each active factor. We also found a significant effect of deeper tailoring on the number of web-based sections of the cessation programming that were opened. The number of sections opened, in turn, was related to 6-month cessation.

Next steps

Using the data of our Phase I screening study, we are developing the elements of our Phase II refinement study. In this study we further develop the potentially active factors from the screening study in an effort to optimize the impact of the Internet-based smoking cessation program.

Implications for cancer prevention & control

Smoking is the leading cause of lung cancer in the world. The reduction of smoking rates must be accomplished through programs that reach millions of smokers, are effective, and can be delivered at low cost. Developing and implementing publicly available web-based smoking cessation programs could have a significant impact on the prevention of lung and other cancers.

Selected publications

Collins, L.M., Murphy, S.A., Nair, V. & Strecher, V. (2005). A strategy for optimizing and evaluating behavioral interventions. *The Annals of Behavioral Medicine, 30,* 65-73.

McClure, J.B., Greene, S.M., Wiese, C., Johnson, K.E., Alexander, G., & Strecher, V. (2006). Interest in an online smoking cessation program and effective recruitment strategies: Results from Project Quit. *Journal of Medical Internet Research, 8*(3), e14.

Primary Project:

Eat for Life – Cultural and Motivational Dietary Message Tailoring

Kenneth A. Resnicow, PhD
Principal Investigator

Problem

Tailoring dietary interventions have considerable promise for cancer prevention. Most previous tailored interventions (as well as interventions for most other health behaviors) have been rooted in the Transtheoretical Model and Social Cognitive Theory as their primary heuristic framework. However, there are numerous intrapersonal and social factors conducive to tailoring that may affect dietary behavior beyond these theoretical constructs. Little is known about tailoring dietary interventions for African American populations.

Disciplines involved

Behavioral science, anthropology, statistics, survey research, software engineering, graphic design, instructional design, and medical care organization.

What we know

We know that there is tremendous diversity in ethnic identity within the African American population. The motives for changing health-related behavior may be divided into intrinsic and extrinsic.

Research questions

Project 2 studies the impact of fruit and vegetable intervention materials tailored to ethnic identity and motivational predisposition.

Methods

Eat for Life is a tailored print-based nutrition intervention seeking to decrease cancer incidence and mortality among 1,000 African American adults. Two psychosocial constructs were used that, to date, have been the subject of little empirical examination: ethnic identity and motivational predisposition. It is designed to identify key elements of cultural and motivational communications that can be used in conjunction with traditional health behavior constructs for increasing fruit and vegetable intake.

In the initial phase of this research, we are identifying key elements of cultural and motivational communications for increasing fruit and vegetable (F & V) intake among a sample of 1,000 African American adults, recruited through two large HMOs, that are candidates for individual tailoring and further exploration in the next research phase.

The initial phase is divided into two studies: Motivational Predisposition and Ethnic Identity. Motivational Predisposition participants are being randomized into an intervention or control group. Ethnic Identity participants in the arm are being randomized into the intervention side or control group. Using psychometric pilot data, an ethnic identity classification system was refined and finalized for use in Phase I. This algorithm will classify each ethnic identity intervention side participant to 1 of 16 single or dual ethnic identity types. Participants in the control groups will receive.

Figure 1. Example of full background, tailored and personalized message to Control 1 participants in the Ethnic Identity study

Results

Data from the psychometric pilot were assessed using factor analysis and cluster analysis to reduce the numbers of items in the ethnic identity and motivational predisposition measures. The reliability of the final scales was quite good, ranging from 0.70-0.79 for the ethnic identity subscales and from 0.89-0.90 for the motivational predisposition subscales. An algorithm was developed to classify respondents according to ethnic identity type. Because many participants were not exclusively high on one ethnic identity subscale and low on the others, the project team allowed either single or dual identity type classifications.

The Motivation Predisposition trial began recruitment in May 2006. The Ethnic Identity trial was launched in August 2006. The psychometric pilot of this project was instrumental in creating the ethnic identity classifications.

Next steps

This research study is in the field with an HMO-based randomized trial to test the impact of F & V consumption materials tailored to ethnic identity and motivation.

Implications for cancer prevention & control

Better reaching traditionally underserved populations through better-tailored behavioral intervention strategies has tremendous implications for cancer prevention and control, recruitment into clinical trials, and long-term cancer survivorship. This study carefully and analytically examines the impact of such interventions.

Selected publications

Stephens, T., & Resnicow, K. (in press) Social cognitive predictors of dietary behavior among African Americans. *Ethnicity & Disease.*

Primary Project:

Guide to Decide – Risk Communication:
A Tamoxifen Prophylaxis Decision Aid

Peter A. Ubel, MD, Principal Investigator

Problem

Guide to Decide is developing, testing, and refining a decision aid to help women decide whether to undergo tamoxifen prophylaxis for primary breast cancer prevention. Tamoxifen prophylaxis involves a trade-off between the inconvenience and side effects associated with taking tamoxifen, and the chance that tamoxifen will reduce one's risk of developing breast cancer. Experts have proposed that decision aids are a promising way to communicate this type of information. But how do we know whether a decision aid has improved women's decisions? Typically, experts have evaluated new decision aids through randomized trials, comparing the decision aid to the standard of care.

Disciplines involved

Behavioral science, medicine, statistics, web-based survey research, software engineering, graphic design, instructional design, and medical care organization.

What we know

Decision aids include of multiple components. Investigators designing decision aids have to make difficult choices: which way to frame risk messages and which mix of prose and/or graphical formats to use for presenting statistical information. This makes it impossible to untangle the effects and determine which components of the decision aid have influenced people's decisions.
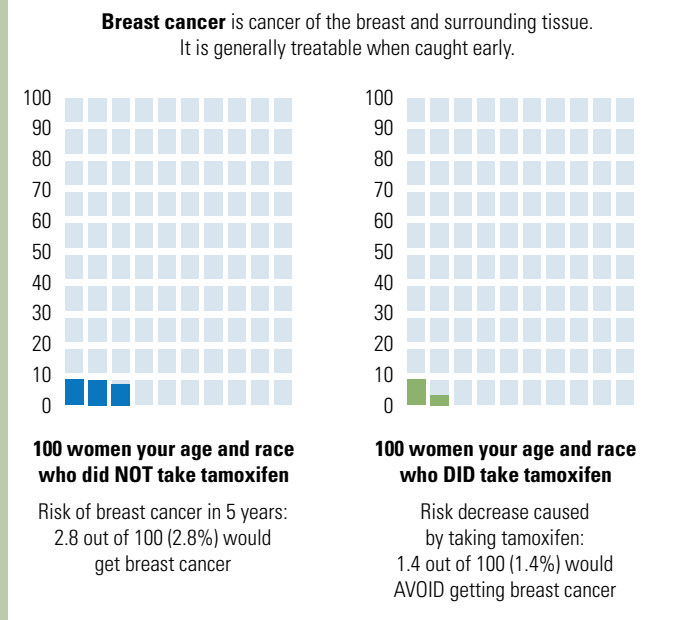
Research questions

We are testing multiple methods for presenting risk information and determining which methods are best for what type of people. We are interested in what methods are most effective for communication statistical information and in what works best across different types of people (e.g., education level, Gail model score, need for cognition).

Methods

Using a fractional factorial design, we will investigate the individual effects of the components of our tamoxifen prophylaxis decision aid, and their interrelationships, by randomizing women to receive various combinations of the components. We will see how each component influences our three primary outcome measures: (1) knowledge of breast cancer risk, (2) satisfaction with the decision aid, and (3) subjective perceptions of tamoxifen prophylaxis. Our project consists of a Phase I screening study and a Phase II refining study. In Phase I we randomized 667 women to receive various combinations of risk messages and graphical formats, using a fractional factorial design. The factors tested were: (1) varying the order of information about the benefits and side effects of tamoxifen; (2) explaining absolute risk reduction using denominators of 100 vs. 1,000 and varying whether relative risk information is included; (3) putting breast cancer risk into context by comparing it to other health risks; (4) presenting risks and benefits using pictographs versus using text only; and (5) presenting risks using additional versus total risk presentation.

Figure 1. Examples of pictograph of breast cancer risk

Breast cancer is cancer of the breast and surrounding tissue.
It is generally treatable when caught early.

**100 women your age and race
who did NOT take tamoxifen**

Risk of breast cancer in 5 years:
2.8 out of 100 (2.8%) would
get breast cancer

**100 women your age and race
who DID take tamoxifen**

Risk decrease caused
by taking tamoxifen:
1.4 out of 100 (1.4%) would
AVOID getting breast cancer

Results

In Phase I, 630 women completed the decision aid. Across all versions of the decision aid, we found that women's knowledge about tamoxifen was high, their worry about breast cancer was low, and their concern about the side effects of tamoxifen was moderate. Overall, women expressed little interest in taking tamoxifen. In analyses of the five factors that made up our decision aid, we found order effects, such that women who learned about the risks of tamoxifen before its benefits were less worried about tamoxifen than those who received information about the benefits first.

Our primary interest was to determine whether any of our other experimental factors eliminated this order effect. One of them did. We discovered that giving women contextual information about their risk of breast cancer eliminated or reduced order effects. We discovered that pictographic representations of risk increased women's understanding of tamoxifen among participants with below average numeracy.

Next steps

In Phase II, we will refine our understanding of the factors that increase the effectiveness of the decision aid in Phase I by isolating specific components of those factors. Given the results of the STAR trial, our Phase II decision aid will contain information about both tamoxifen and raloxifene. STAR (Study of Tamoxifen and Raloxifene) was a clinical trial testing the effectiveness of both tamoxifen and raloxifene in preventing the occurrence of breast cancer in women at an increased risk of developing it.

Implications for cancer prevention & control

Whet her taking tamoxifen is right for a woman will often depend on her preferences. To make informed decisions about whether to take tamoxifen, women need to understand their baseline risk of breast cancer as well as the risks and benefits of tamoxifen prophylaxis.

Selected Publications

Zikmund-Fisher, B.J., Fagerlin, A., & Ubel, P.A. (2005). What's time got to do with it? Inattention to duration in interpretation of survival graphs. *Risk Analysis, 25,* 589-595.

Fagerlin, A., Zikmund-Fisher, B.J., & Ubel, P.A. (2005). How making a risk estimate can change the feel of that risk: shifting attitudes toward breast cancer risk in a general public survey. *Patient Education and Counseling, 57,* 294-299.

Pilot Project:

Web Survey Nonresponders – Design of Effective Web Data Collection for Cancer Prevention Studies

Mick P. Couper, PhD, MPH
Principal Investigator

Problem

The World Wide Web is an attractive option for the implementation of surveys, but it suffers from potential limitations, including nonresponse. To the extent that the probability to respond to a survey request is associated with measures of interest, inferences from the survey will be erroneous. One such example is when the effectiveness of an experimental intervention affects the propensity to respond to a follow-up survey. This can lead to misleading conclusions both about the difference between the experimental and control groups, and the actual direction and magnitude of effect.

Disciplines involved

Survey researchers, software engineers, and software engineers.

What we know

The reasons for nonresponse to web-based surveys are different than the reasons for nonresponse to telephonic or mailed surveys, and that web response rates are lower.

Research questions

This study's primary goal is to identify possible bias from web survey nonresponse in parallel with the core research activities of the CECCR research projects.

Methods

Through another study, 3,260 subjects were recruited in three U.S. regions for a randomized experiment of an online weight management intervention. Participants were sent invitations to web-based survey reassessments after 3, 6, and 12 months. High and increasing nonresponse to the three follow-up surveys created the potential for nonresponse bias in key program outcomes. A subsample of the nonrespondents at the 1-year follow-up was selected for this study. This subsample was then randomly assigned to a short telephone (n=300) or mail (n=400) survey. This was done in order to evaluate cost efficiency, differential effectiveness of mode combinations in reducing nonresponse bias, and measurement differences by mode. The responses from the nonresponse study were then added to the baseline measures and used in an imputation model.

Results

The overall response rate was 57% (59% for phone and 55% for mail). Overall weight loss outcomes among nonrespondents are similar to respondents. We also found a significant effect of the method of surveying nonrespondents (i.e., phone vs. mail). An effort to develop a multiple imputation scheme to reconstruct the full data set was partially successful, but the high rate of initial nonresponse, the small number of nonrespondents included in the follow-up study, and the use of both telephone and mail led to unstable estimates. Nonetheless, the data from the nonresponse follow-up study helped us conduct sensitivity

Figure 1. Treatment/Control vs. BMI

Figure 1. Treatment/Control vs. BMI
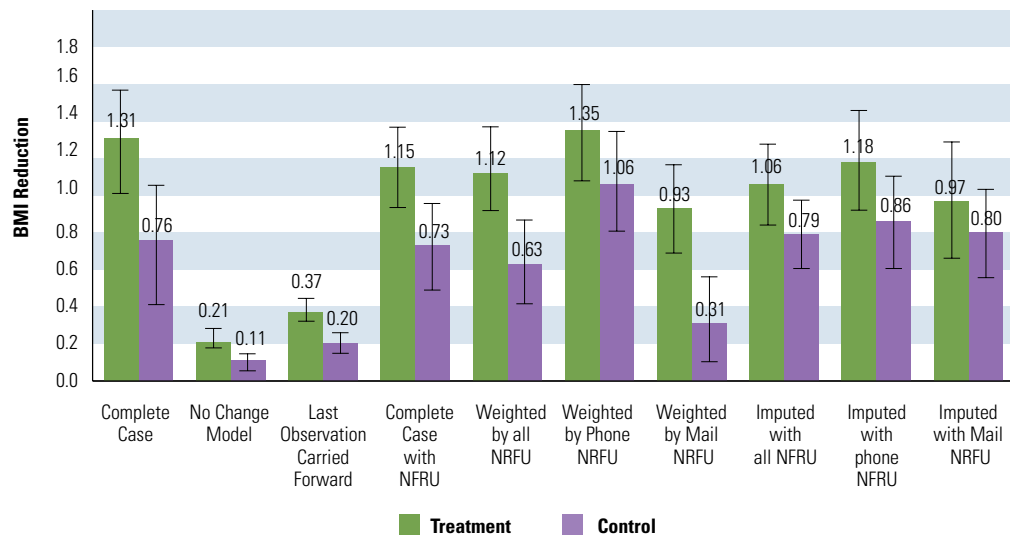
analyses of the 12-month outcomes, as shown in Figure 1. These results represent the first endeavor to study nonrespondent bias in a health-related web-based intervention study.

Next steps

The results were very promising. A similar nonresponse follow-up study has been carried out as part of another online weight management trial funded by the Robert Wood Johnson Foundation. In this work, a mail-only follow-up of nonrespondents yielded a 63% response rate, and a significantly larger number of respondents (568), to permit extension of the modeling procedures developed in the initial nonresponders study. Preliminary results also demonstrate a similarity in weight loss outcomes between nonrespondents and respondents.

Implications for cancer prevention & control

Because web-based data collection involves a low per-unit cost as well as a viable means of implementing complex designs, results from this study will have major benefits both for the CECCR research projects and for the broader health research community. For example, results of this study will be relevant to long-term, longitudinal, web-based assessment cancer survivors. As CECCR projects (all of which are focused on cancer prevention) are launched via the web, several theory-based tailored interventions will be implemented within the studies to minimize the effect of nonresponse.

Selected publications

Couper, M.P., Kapteyn, A., Schonlau, M., & Winter, J. (2007). Noncoverage and nonresponse in an internet survey (in press). *Social Science Research.*

Pilot Project:

Stepping Up to Health – Automated Step-count Feedback to Promote Physical Activity in Chronic Diseases

Caroline R. Richardson, MD
Principal Investigator

Problem

Many American adults are sedentary, and most are not physically active at levels that can promote health and potentially reduce the risk of cancer. An estimated 25% of American adults report no leisure-time physical activity, which has not changed significantly since 1988 (Ham et al., 2004). Studies have shown a significant inverse relationship between physical activity and several diseases, including the many cancers (Giovannucci et al, 1995, 1996; Martinez et al., 1997). For inactive people, even small increases in physical activity are associated with measurable health benefits (Simpson et al, 2003). Moderate physical activity is more readily adopted and maintained than vigorous physical activity (USDHHS, 1996). Walking is a popular mode of physical activity with an estimated 4 in 10 American adults that walk for exercise. Programs that use pedometer feedback increase walking more than those that use time-based walking goals (Hultquist et al., 2005).

Disciplines involved

Behavioral science, medicine, statistics, web-based survey research, software engineering, graphic design, and instructional design.

What we know

Setting goals motivates more positive behavior than "do your best" requests. Pedometry is readily accepted by a broad range of individuals.

Research questions

Does counseling and feedback that emphasizes a 10-minute minimum duration for physical activity bouts result in a different pattern of walking behavior compared to counseling and feedback focusing only on total daily accumulated steps?

Methods

Stepping Up to Health is an Internet-mediated intervention to increase the number of people with chronic diseases to walk. A unique component of the intervention is that participants can automatically upload time-stamped step-count data over a USB port directly from their study pedometer to the web site. Users can then view graphs of their step-counts, monitor their success in achieving daily step-count goals, and receive tailored motivational messages. The step-count graphs and tailored feedback help people increase their walking by improving the user's ability to self-monitor their walking behavior.

This was a 7-week randomized controlled trial in which 37 participants were randomized to one of two intervention arms. All wore an Omron pedometer with a built-in USB port all day, every day, and uploaded their step-count data to their personal web page. Those randomized to the "total step" group received walking goals and feedback based on total daily accumulated steps, while those randomized to the 10-minute "bout" group received goals and feedback only on steps taken during walking bouts of at least 10-minute duration.

Figure 1.   Example of step-count graphs and tailored feedback message
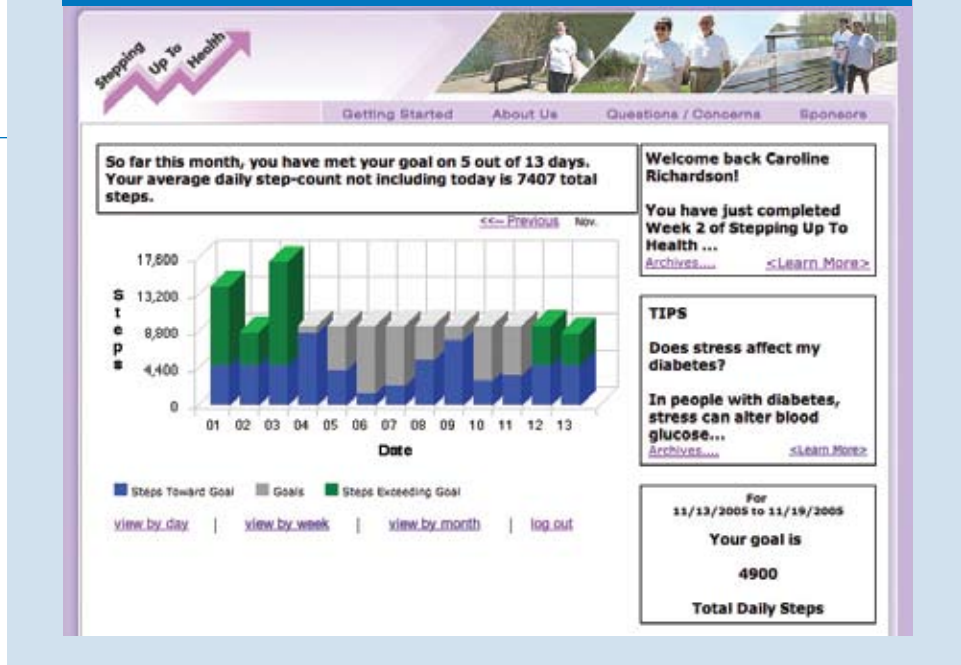
Results

Participants in two goal-setting intervention arms increased their average daily total step counts by almost 2,000 steps (~1 mile) from the mean baseline of 4,596 steps/day to the mean final total step count of 6,534 steps/day (p = 0.0032). Both groups increased steps taken during walking bouts (bout group increase = 2,101 bout steps, p = 0.0196; total step group increase = 1,783 bout steps, p = 0.0164).

Next steps

A randomized trial varying strength of goals set (high vs. low) and type of feedback framing (positive vs. negative) has been submitted as an R01 to NCI.

Implications for cancer prevention & control

The most definitive epidemiologic evidence for an association between physical activity and cancer exists for colon cancer. Numer-ous observational studies, representing over 13,000 colon cancer cases, have found an inverse association between physical activity and risk of colon cancer. (Friedenreich and Orenstein, 2002) This relationship has been observed in men and women of all ages, and in various racial and ethnic groups in diverse geographic areas around the globe. In all of nine cohort studies the relative risk for colon cancer was decreased in persons in the highest category of either recreational or occupational (depending on which was measured) physical activity, compared with persons in the lowest category, with relative risk estimates ranging from 0.40 to 0.90 (Giovannucci et al., 1995, 1996; Martinez et al., 1997).

Selected publications

Richardson, C.R., Brown, B.B., Foley, S., Dial, K.S., & Lowery, J.C. (2005). Feasibility of adding enhanced pedometer feedback to nutritional counseling for weight loss. *Journal of Medical Internet Research, 7,* e56.

Pilot Project:

Neural Imaging to Study the Impact of Personally Tailored Health Communication

Victor J. Strecher, PhD, MPH
Principal Investigator

Problem

Cancer prevention and control messages tailored to an individual's specific needs and interests have been shown to be more effective in inducing health behavior change better than nontailored messages. Moreover, as we have recently found in the initial phase of Project Quit, behavior change and the perceived relevance of the message increases with the depth of tailoring. While we know from Dr. Kreuter's research at Saint Louis University, tailored messages are more likely to elicit cognitive consideration (elaboration) than untailored messages. We know little, however, about how the brain processes high- versus low-tailored health behavior change messages.

Disciplines involved

Behavioral science, medicine, statistics, and physics.

What we know

We have found in an initial study of tailored smoking cessation programming that "perceived relevance" of the cessation materials was an important mediator in quitting smoking. In other words, smokers who received increasingly tailored smoking cessation materials were more likely to find these materials "written for them." This measure of personal relevance was, in turn, predictive of smoking cessation when

adjusting for treatment condition. Along similar lines, social psychologists have found that materials considered more personally relevant promote greater cognitive activity and elicit higher amplitudes of attitude change (positive and negative) depending on the strength of the message than do less relevant messages (Darke and Chaiken, 2005). Along parallel lines, one of the new collaborators in the CECCR, Dr. Liberzon and colleagues, have found that stimuli considered personally relevant (what they have termed "salience") stimulate activity in particular parts of the brain (specifically the ventral medial prefrontal cortex).

Research questions

We are comparing neural activation patterns of study participants who want to quit smoking when being read highly tailored vs. low tailored health messages that promote smoking cessation. We are examining whether highly tailored health messages would activate the ventro-medial prefrontal area more than low-tailored messages.

Methods

This is a within subjects design. Participants will be briefed about the study, asked to provide consent, then asked to complete a baseline survey about their smoking habit, barriers to quitting, and reasons to want to quit (used for creating the tailored messages). The study coordinator will then schedule an appointment with the participant for a functional magnetic resonance imaging (fMRI) scan experiment session. Scanning will

Figure 1. Brain activity related to volitional appraisal of self-relatedness
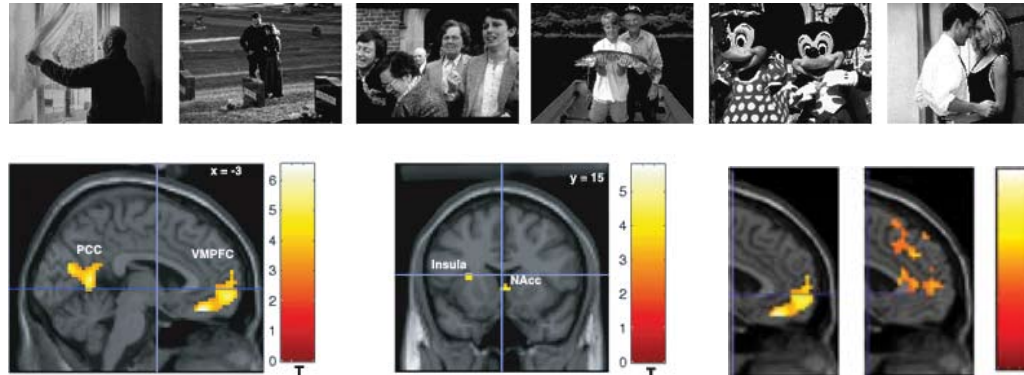
Random-effects statistical parametric activation map (SPM; T score >3.17, P < 0.005, uncorrected) (A) activation in the ventral medial prefrontal cortex (VMPFC) during volitional appraisals of personal association (ASSOCIATION task) compared to explicit judgments of emotional/valence intensity (VALENCE task); and (B) additional activation of dorsal medial prefrontal cortex (DMPFC) and anterior cingulate cortex (ACC) with increasing self-relatedness during the ASSOCIATION task.

occur on a 3.0T GE Signa scanner. During the actual fMRI task, participants will listen to high-tailored and low-tailored messages related to quitting smoking. Participants' brain activity will be scanned while they hear these messages. In this blocked design, there will be 6 runs consisting of 10 trials, for a total of 60 trials throughout the session. After the scanning session, participants will read the smoking cessation messages they just listened to. They will then complete a post-session survey to tell us what they think about the messages. Responses to the survey can be used as potential regressors for the activation signals.

Results

This study will be fielded in the fall of 2006, continuing for approximately 12 months.

Next steps

This study, in combination with an eye-scanning study of tailored materials, is attempting to determine the metrics of physiological response to highly tailored materials. Future studies may examine the impact of these physiological responses to long-term behavioral outcomes.

Implications for cancer prevention & control

This study, along with a complementary eye-scanning study, is intended to enhance the signal-to-noise ratio of cancer prevention and control communications. This will be particularly important as tobacco companies utilize similar technologies in targeting customers and potential customers with pro-tobacco messages.

University of Pennsylvania

Effects of Public Information in Cancer (EPIC) Center

What is the CECCR at Penn about?

Our base assumption is that important decisions about cancer, including those related to prevention (e.g., smoking, diet, physical activity), screening, and post-diagnosis treatment and survival reflect, in part, the influence of mass media, the Internet, and other public information sources. The scientific goals of the Effects of Public Information in Cancer (EPIC) Center at the University of Pennsylvania are (1) to understand how people make sense of the complex public information environment and how these perceptions affect the behavioral choices they make relevant to cancer, and (2) to support development of communication interventions that are efficacious in producing cancer-related behavior change.

The CECCR at Penn includes three central and closely linked elements: the primary major research projects; the program of smaller scale pilot and spin-off research; and the effort to train doctoral students in communication and post-doctoral trainees drawn from communication and other disciplines. The CECCR links several important institutional entities, including the Annenberg School for Communication, the Abramson Cancer Center, and the Leonard Davis Institute for Health Economics.

Primary research

Primary research is conducted under three R01s. Project one, led by Robert Hornik, PhD, director of the EPIC CECCR, seeks to understand what public communication channels currently use when they make decisions about prevention, screening, and post-diagnosis treatment and survival. This project considers exposure to public information sources that are used more passively (scanning) and public information sources that are used actively (seeking.) This project asks how people vary in their seeking and scanning behavior, what influences that variation, and, most importantly, how differences in seeking and scanning lead to different decisions about cancer-related behavior. The expectation is that this information will lead to more productive ways to disseminate cancer information on a large scale, informed by knowledge of the current use of communication sources.

Project two, led by Caryn Lerman, PhD, focuses on designing and evaluating messages to increase smoking cessation treatment seeking in adult smokers. Using an experimental design, this project compares anti-tobacco advertisements that vary on the strength of the central arguments for quitting smoking and the nature of the production format (high vs. low message sensation value).

Key outcome measures include subjective measures of persuasion, and objective measures of attention and arousal (i.e., psychophysiological assessments). The project tests the relative contributions of these measures to actual treatment seeking for smoking cessation. This is both a study in basic theory of message design and an applied study. The ultimate goal is to provide an empirical basis for the design and evaluation of anti-smoking messages and to enhance the impact of these messages on smoking-related behaviors.

Project three, led by Joseph Cappella, PhD, focuses on a message design question in a smoking context as well. It recognizes that developments in molecular genetics have been growing at a very rapid pace and will continue to do so in the near future. Accompanying these developments are a very strong interest in genetics by the news media and the possibility that the public will infer incorrectly that genetic susceptibility to disease or behavior means they have lost control of their lives. The study assesses how genetic information is now presented in the media. The central research experiment tests messages that differ with respect to (1) the framing of genetic information, (2) the presence of information about efficacy to act in a healthy way, and (3) the use of case examples. The question is whether these media messages about genetics produce an increased sense of fatalism versus empowerment with regard to quitting smoking, and whether that result depends on how the story is told.

The results of this study may produce advice to journalists about what the effects of alternative approaches to telling the genetic story would be as well as information about the role of pharmaceutical interventions ("remedies") in motivating treatment-seeking by smokers.

To complement the work conducted under the three primary R01s, the EPIC Theory and Methods Core, directed by Martin Fishbein, PhD, explores theoretical and methodological approaches to cancer communication research and behavior change. One project compares the role of injunctive norms versus descriptive norms in cancer prevention and screening behavior. The Core led conferences on message theory and genetic communication.

Pilot and spin-off research

While these big research projects were the core of the original proposal, they are only a part of the research that is linked to the CECCR. Two other types of research have been supported since the outset: formal pilot projects and spin-off studies.

Since its inception, the EPIC Center has funded nine formal pilot projects exploring frontier areas of cancer communication research. Areas of investigation include direct to consumer advertising of both prescription drugs and genetic testing for breast cancer; cancer information-seeking and -scanning behavior among Vietnamese immigrants; reactions among African Americans to media messages about differences in the genetic risks of smoking; and differences in how media targeted to different racial groups portray end-of-life decisions. There are a number of

linked studies that test additional objective measures of the effectiveness of anti-tobacco ads. These include a study using eye-tracking measures and one using functional magnetic resonance imaging (fMRI).

Along with the formal pilot projects there have been an even larger set of 14 spin-off projects, research closely linked to one of the R01 projects but asking discrete questions using additional methods and often with complementary funding from other sources, and led by post-doctoral or doctoral-level trainees. One of the early spin-off projects (the Quest® study) was the foundation for a R01 grant submission concerning similar products and compensatory smoking. Two other grant proposals currently under National Institutes of Health (NIH) review came directly from CECCR research. Two of the EPIC Center pilot projects have been awarded external grant funding. Eight of the other spin-off projects have received additional support from internal university sources.

Building the pool of cancer communication researchers

The EPIC Center is committed to training a new generation of researchers in rigorous approaches to cancer communication research. Our faculty researchers have been drawn from four schools of the university (Medical, Annenberg, Wharton, and the School of Arts and Science) and many disciplines (communication research, medicine and health services research, oncology, psychiatry, clinical and social psychology, statistics, genetics, and anthropology). More importantly, 15 doctoral students and 12 post-doctoral-level trainees/research directors have been active in the CECCR. All have or will publish in cancer communication, and most of the doctoral students will do cancer communication-related dissertations. Three of the post-doctoral researchers have now gone on to university faculty positions, and two of the doctoral students have gone on to prestigious fellowships. Annenberg attracts the strongest communication graduate students in the country; they are now focusing on cancer communication because of the CECCR.

Primary Project:
The Seeking and Scanning Behavior Project

Problem

Decisions about cancer prevention, screening, and treatment may be influenced by media and personal sources of varying quality along with medical sources. How does use of public media sources affect specific cancer-related decisions?

Disciplines involved

Communication research, oncology, health services research, public health.

A central concept

Seeking *behavior is active looking for specific information.*

Scanning *behavior is attention to information seen or heard through routine use of media.*

Research questions

1. How much seeking and/or scanning behavior is reported related to specific prevention (diet, exercise, fruit and vegetable consumption), screening, and post-diagnosis decisions for colon, breast, and prostate cancer?

2. Who does more and who does less seeking and/or scanning behavior (by gender, race-ethnicity, education, personal history, others)

3. What influence does seeking and/or scanning behavior have on cancer-related behaviors?

Methods

1. General population: an in-depth interview study (N=88) and two-round national sample survey study (N=2400) of 40- to 70-year olds.

2. Cancer patients: an in-depth interview (N=45) and a two-round Pennsylvania statewide sample survey (N=2000) of breast, colon, and prostate cancer patients drawn from the Pennsylvania Cancer Registry.

Results

■ Scanning is more common then seeking; both vary by behavior.

■ Seeking and/or scanning behavior varies by gender, education, but not race-ethnicity.

■ Seeking and/or scanning behavior is strongly associated with recommended screening and prevention behaviors, but causal claims await prospective data (see Figure 1).

Figure 1. Relative odds of doing six behaviors by whether did or didn't scan or seek
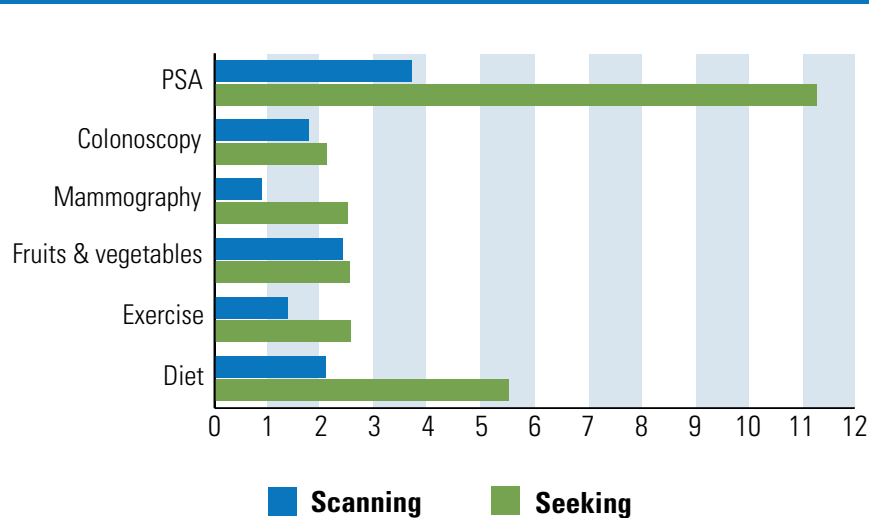
Next Steps

1. The second round of the general population survey is underway; the second round of the cancer patient survey will begin in summer 2007.

2. Analyses will examine, prospectively, determinants of seeking and/or scanning behavior and cancer-related behavioral consequences of seeking and/or scanning behavior.

Implications for cancer prevention & control

1. Evidence about whether use of public information contradicts or reinforces medical system recommendations will define needed communication efforts.

2. Evidence about sources of information people actually rely on in making cancer decisions will support choice of diffusion channels that reach the majority of the population.

Selected publications

Niederdeppe J., Hornik, R., Kelly, B., Frosch, D., Romantan, A., Stevens, R., & Weiner, J. (in press). Exploring the dimensions of cancer-related information seeking and scanning behavior. *Health Communication*.

Shim, M., Kelly, B., & Hornik, R., (2006). Cancer information scanning and seeking is associated with knowledge, lifestyle choices and screening behavior. *Journal of Health Communication, 11*(Suppl. 1), 2.

Primary Project:

Biobehavioral Evaluation of Anti-tobacco Public Service Announcements

Problem

Despite the widespread use of anti-tobacco public service announcements (PSAs) to promote smoking cessation, there has been little theory-driven experimental investigation of the features that influence PSA effectiveness. Two features of the PSAs that may be important to effectiveness are Argument Quality (weak vs. strong) and Message Sensation Value.

Argument Quality (AQ)
Strength of central reason provided for quitting smoking, as rated by smokers.

Message Sensation Value (MSV)
Coding of formal features of PSA (e.g., edits, sounds) related to novelty and intensity.

Disciplines involved

Communication research, biobehavioral research, public health.

Research questions

1. Do Argument Quality and Message Sensation Value influence smokers' psycho-physiological, cognitive, and behavioral responses when viewing anti-tobacco PSAs?

2. What is the relationship between physiological responses and persuasiveness of the PSAs?

Methods

1. Smoking-related PSAs (n=600) were categorized by topic and audience. Ninety-nine PSAs focused on smoking cessation and targeted to adults were selected and coded for Message Sensation Value. For each PSA, the central argument was extracted and evaluated for Argument Quality.

2. Smokers (n=300) were recruited nation-wide to validate Argument Quality for the 99 PSAs. The Argument Quality measure was found to be highly internally consistent and correlated with measures of intentions to quit smoking and perceived vulnerability.

3. PSAs were selected for empirical evaluation in a media laboratory experiment using a 2 x 2 factorial design (Hi vs. Lo Message Sensation Value; Hi vs. Lo Argument Quality) with 160 smokers.

Participants attend a single laboratory session where they view four PSAs during monitoring of heart rate (for attention and arousal), skin conductance response (for arousal), and zygomatic and corrugator EMG (for affect: smiling and frowning). Self-report measures of persuasion and calls to a quit line are used to assess outcome.

Figure 1. Effect of Public Service Announcement manipulation on preliminary data

Heart rate change (n=66)

SCR change (n=66)

Zygomatic (EMG) (n=66)

Corrugator (EMG) (n=66)
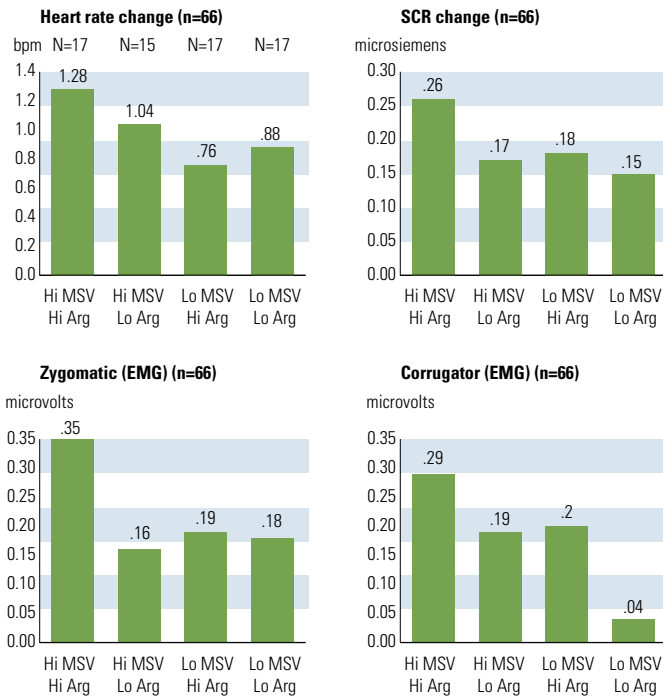
Figure 2. Effect of Public Service Announcement manipulation on preliminary data

Intent try to quit (n=66)

Intent will quit (n=66)

Attitudes (n=66)

Efficacy (n=66)
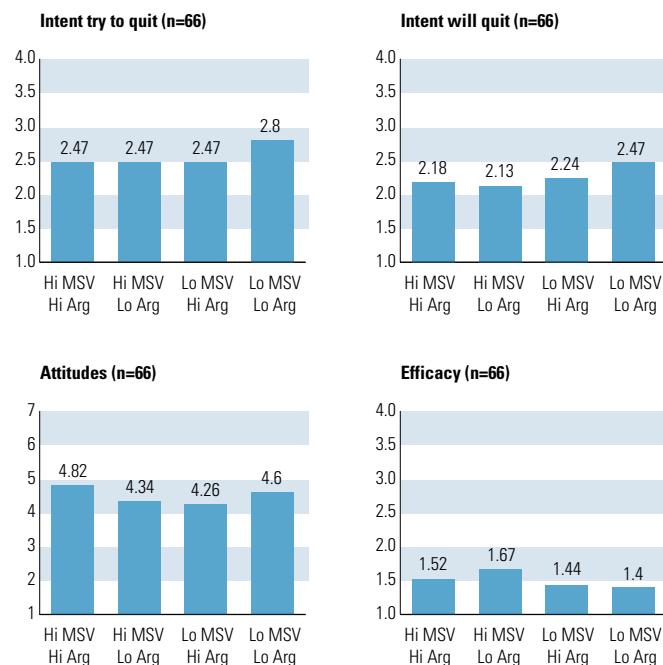
Results

Preliminary data for the first 66 participants are shown in Figures 1 and 2. These data suggest that physiological measures may be more sensitive to manipulations of PSAs features than self-report measures. Data were presented at Society for Research on Nicotine and Tobacco, 2006.

Next steps

The PSAs utilized in this ongoing study are being evaluated on additional biobehavioral dimensions using functional magnetic resonance imaging (fMRI) and eye-tracking techniques. Ongoing studies are also evaluating smokers' physiological responses to smoking cues included in the PSAs.

Implications for cancer prevention & control

By understanding the biological basis of the persuasiveness of anti-smoking PSAs, we hope to generate a novel, empirically based paradigm for development and evaluation of countermarketing strategies.

Primary Project:

Communicating Genetic Risk in the Media: Effects on Efficacy and Healthy Behavior

Problem

The quantity and variety of information in the public arena about genetic influences on disease and behavior is growing rapidly as the science advances. However, it is unclear whether genetic risk information encourages or discourages healthy behaviors to prevent cancer. Genetic risk information (e.g., about tobacco addiction) could increase determination to adopt a healthy lifestyle or it could lead to a belief that healthy behavior is out of a person's control. This question is a precursor to one about framing genetic risk so as to encourage healthy action and reduce fatalistic views.

Disciplines involved

Communication, oncology, public health, journalism.

What we know

Theories of behavior change suggest that individuals who believe they are at higher personal risk of developing cancer are more likely to engage in cancer risk-reduction activities. However, heightened risk perceptions may reduce their confidence that they can act (called self-efficacy). Communicating genetic risk in counseling or educational contexts has had not always produced beneficial results.

Research questions

1. How does the framing of genetic risk information (e.g., certain and uncertain) affect behaviors that prevent cancer?

2. Will the delivery of efficacy information personalized to the audience (exemplars) alter the impact of genetic risk information on the uptake on healthy behaviors?

3. What mechanisms explain how genetic risk information affects healthy behavior?

Methods

Five analyses have tested effects of genetic risk information on self-efficacy and intention to engage in healthy behaviors. The studies had common outcome measures: inference of genetic susceptibility, personal self-efficacy, and behavioral intention, but differed in substantive contexts: quitting smoking (3), obesity reduction (1), and osteoporosis and heart disease (1). Samples are nationally representative (total N=1817).

Results

The analyses show that exposure to genetic risk information affects persons' inferences that they are genetically susceptible. This inference has contradictory effects: On the one hand, it directly increases intention to change behavior; on the other, it reduces self-efficacy, which then lowers the intention to change behavior. Overall the effects have roughly equal impact (see Figure 1).

Figure 1. Summary model for at-risk groups

Implications for cancer prevention & control

Genetic risk information appears to have two sides. The challenge is to ensure that it motivates healthy lifestyle choices and does not undermine self-efficacy.

Selected publications

Cappella, J.N., Lerman, C., Romantan, A., & Baruh, L. (2005). News about genetics and smoking: Priming, family smoking history, and news story believability on inferences of genetic susceptibility to tobacco addiction. *Communication Research*, 32, 478-502.

Next steps

How can information about genetic risk be presented so that it increases healthy behavior without undermining self-efficacy? Some research suggests that among high-risk groups, including remedies (e.g., nicotine replacement therapy for smokers) can have deleterious effects by lowering risk perceptions and reducing intentions to choose healthy options.

Next studies will test the effects of incorporating efficacy information along with genetic risk information on treatment-seeking for smoking. They will examine the effects of treatments for quitting on quitting behaviors moderated by personalized versus non-personalized genetic and efficacy messages.

Pilot Project:

New Lower Nicotine Cigarette Product: Smokers' Inferences from Advertisements and Product Safety

Problem

Quest® cigarettes are a new brand of low-nicotine cigarettes that have been marketed as a way for smokers to gradually reduce the nicotine they receive from cigarettes. Despite lower levels of nicotine, *Quest cigarettes do not have reduced tar levels and contain carcinogenic constituents in the tobacco.* Given that this product is not likely to be a safer cigarette, it is important to understand how smokers perceive this newly marketed low-nicotine cigarette and how it affects smoking behavior and disease risk.

Disciplines involved

Communication research, biobehavioral research, cancer biology.

Research questions

1. To examine the prevalence of false inferences about the safety of Quest cigarettes and explore factors associated with the likelihood of false inferences.

2. To determine whether smokers compensate for the lower nicotine levels in Quest cigarettes by increasing puffing, thereby, increasing exposure to carcinogens in tobacco.

Methods

Smokers (n=200) were recruited using a mall intercept survey approach. Smokers viewed a single Quest cigarette print advertisement for 30 seconds and then completed a survey. A parallel study in the biobehavioral laboratory at the Transdisciplinary Tobacco Use Research Center (TTURC) was conducted to determine the extent of compensatory smoking when switching to lower nicotine Quest cigarettes. While smoking each Quest cigarette (nicotine levels of 0.6 mg, 0.3 mg, and 0.05 mg) through a smoking topography device, puff volume and velocity, and carbon monoxide boost were measured in 50 smokers.

Results

Many smokers made false inferences about Quest cigarettes: 40% believed Quest cigarettes would help them quit smoking, and 30% believed Quest cigarettes were safer (see Figure 1).

The results of the smoking topography study provided evidence for significant compensatory smoking and increased carbon monoxide exposure while smoking the reduced nicotine level Quest cigarettes (see Figure 2). Thus, although these cigarettes may increase carcinogen exposure, a majority of smokers infer from the advertisements that these cigarettes may be less harmful.

Next steps

Dr. Strasser (Principal Investigator) has a pending NCI RO1 (5.9 percentile) to study smoking compensation and carcinogen levels in smokers who use Quest cigarettes for an extended period. In addition this project will examine the extent to which false inferences about product safety from the advertisements influence smoking behavior and carcinogen

Figure 1. Prevalence of false inferences about the safety of Quest® cigarettes

- Help people quit smoking
- Make smoking safer
- Are healthier
- Are less likely to cause cancer
- Are lower in tar
- Are lower in nicotine

0 20 40 60 80 100

True Unsure Not true
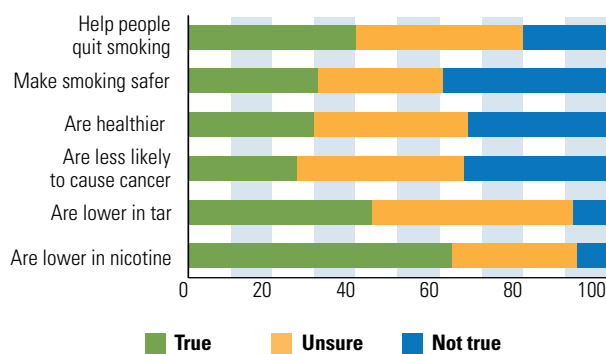
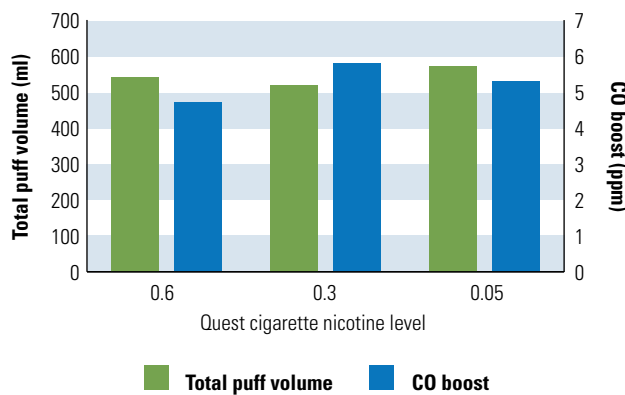**Figure 2. Total puff volume (ml) and CO boost (ppm) when smoking Quest® cigarettes**

Total puff volume (ml) — 0, 100, 200, 300, 400, 500, 600, 700
CO boost (ppm) — 0, 1, 2, 3, 4, 5, 6, 7
Quest cigarette nicotine level — 0.6, 0.3, 0.05

Total puff volume CO boost

exposure. A second study, currently underway, examines the effect of advertisement components (text, color, and graphics edits) on false inferences about Quest cigarettes.

Implications for cancer prevention & control

Study results indicate that advertisements for Quest cigarettes create misperceptions among consumers about the health and safety of these tobacco products despite the potentially *increased harm of these products due to compensatory smoking.* These results reinforce the need for public health awareness campaigns to relay the message that smoking any cigarettes—regardless of nicotine content–can have deleterious health effects.

Selected publications

Shadel, W., Lerman, C., Cappella, J., Strasser, A., Pinto, A., & Hornik, R. (2006). Evaluating smokers' reactions to advertising for new lower nicotine Quest® cigarettes. *Psych Add Beh, 20*(1), 80-84.

Strasser, A., Lerman, C., Sanborn, P., Pickworth, W., & Feldman, E. (in press). New lower nicotine cigarettes can produce compensatory smoking and increased carbon monoxide exposure. *Drug Alcohol Depend.*

Pilot Project:

Normative Influence on Cancer-related Behaviors

Problem

Individual decisions to perform cancer-related behaviors may reflect the influence of others (called normative influence). This study examines what kinds of normative influence affect what kinds of cancer-relevant behaviors. Two kinds of norms are examined: descriptive (the perception of what others are doing) and injunctive (what others think I should do). Two classes of cancer-relevant behaviors are included: screening for three different cancers and three lifestyle behaviors (eating five or more servings of fruits and vegetables a day, exercising at least three times a week, and dieting to control weight).

Research question

Do descriptive norms and injunctive norms increase our ability to account for people's intentions to engage in cancer screening and healthy lifestyle behaviors over and above the effects of typical predictors such as attitudes toward the behavior and a belief that a behavior is under an individual's control?

Descriptive
The perception of what others are doing.

Injunctive
What others think I should do.

Methods

Using a nationally representative sample of 1,753 (879 female, 874 male) adults between the ages of 40 and 70 we measured intentions to get screened for these three types of cancer and to engage in the three healthy lifestyle behaviors.

For each behavior, we measured perceptions of what important others thought they should do (IN), perceptions of what others are doing (DN), their attitudes toward performing these behaviors (ATT), and their perceptions of the amount of control they have over performing each behavior (PBC).

What we learned

Injunctive norms are moderately or strongly associated with intentions to engage in all three cancer screening behaviors as well as in dieting for weight control.

Descriptive norms are moderately associated with intentions to eat five or more servings of fruits and vegetables over and above the effects of injunctive norms. Neither norm was a substantially associated with exercise (see Table 1).

Table 1. Percentage of variance accounted for in behavioral intentions at each step

Behavior	Attitude & perceived behavioral control (%)	+ Injunctive norm (%)	+ Descriptive norm (%)
Mammogram	40.5	7.0	0.8
Colonoscopy	35.2	15.8	1.0
PSA test	36.6	14.0	1.5
Exercise	52.9	0.0	0.7
Fruits & vegetables	37.3	2.3	4.7
Diet	49.2	6.0	0.2

Implications for cancer prevention & control

Interventions to influence the three screening behaviors and dieting may differ from those addressing fruit and vegetable consumption. For screening and dieting behaviors, convincing people that other important people in their lives think they should act will be particularly important. Spouses or friends can be encouraged to use their influence. In contrast, for fruit and vegetable consumption, convincing people that others like themselves perform those behaviors will be important. For exercise, norm-focused messages may not be effective.

Next steps

Analyze effects prospectively, with behavior as the outcome, as second round data from this sample becomes available (Seeking and scanning project). This will increase confidence in causal claims. An R01 grant proposal is under review to conduct a meta-analysis examining the roles of different social norms across behaviors, populations, and contexts to better understand their theoretical and practical role in decisionmaking.

Pilot Project:

Smokers' Craving Responses to Anti-tobacco Public Service Announcements

Problem

Anti-tobacco PSAs commonly used in campaigns to promote smoking cessation often include smoking cues (scenes with cigarettes). The ads vary considerably in the strength of the arguments they employ.

Research on smoking cues in other contexts shows that the smoking urge can be elicited in response to cue presentation. Smoking cues in anti-smoking PSAs could create craving responses in smokers undermining the effectiveness of anti-smoking arguments. This pilot research is supported by the CECCR and conducted by Yahui Kang as a part of her dissertation addresses this problem.

Argument Quality (AQ)

Strength of central reason provided for quitting smoking, as rated by smokers.

Message Sensation Value (MSV)

Coding of formal features of PSA (e.g., edits, sounds) related to novelty and intensity.

Disciplines involved

Communication research, biobehavioral research, public health.

Research questions

1. Do smoking cues in anti-smoking PSAs increase smokers' self-reported urge to smoke compared to no-cue ads?

2. Will smokers' cravings be moderated by the quality of the ad's arguments (strong vs. weak) against smoking?

3. Will smokers' psychophysiological, cognitive, and behavioral responses when viewing be moderated or mediated by their self-reported craving?

Methods

1. From an archive of smoking-related PSAs (n=600), 12 PSAs focusing on smoking cessation and targeted to adults were selected. Six had smoking cues or scenes and 6 did not. Three smoking cue and 3 non-smoking cue ads had strong arguments. Six had weak arguments. The 12 ads were matched on how arousing they were using message sensation value.

2. Smokers (n= 100) viewed and evaluated ads.

3. PSAs were viewed in a media laboratory experiment using a 2 x 2 mixed design (Cue vs. No Cue [within subjects]; High

vs. Low Argument Quality). Participants attended a single laboratory session where they viewed six PSAs during monitoring of heart rate (for attention and arousal), skin conductance response (for arousal), and zygomatic and corrugator EMG (for affect: smiling and frowning). Self-report measures of smoking urge were obtained at four points in time along with intention to seek treatment and recall of central and peripheral features of the ads immediately and 1 week later.

Figure 1. Self-reported changes in smoking urge
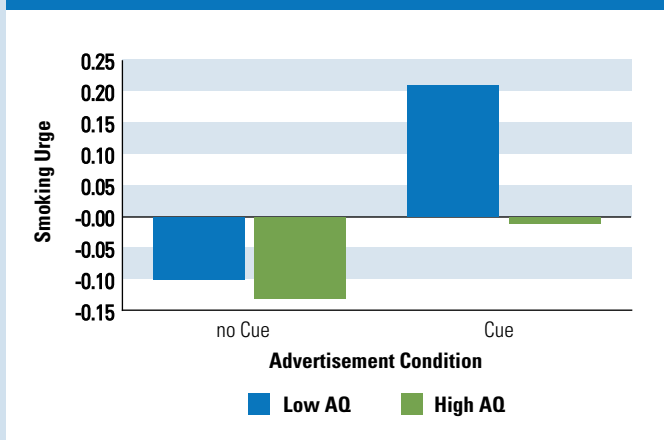
Results

Preliminary results for smoking urge indicate that craving was stronger after viewing ads with smoking cues but only when PSAs were low AQ (weak arguments); ads with high AQ (strong arguments) against smoking showed less smoking urge ($p <= .05$) (see Figure 1).

Next steps

The data obtained in this study have just begun to be analyzed. The role of smoking urges in moderating and mediating effects on psychophysiological, cognitive, and intention-to-quit measures are being evaluated.

Data for smokers' visual attention to smoking cues in anti-smoking PSAs have been obtained in a separate study. These data will provide additional evidence about visual attention to smoking cues by smokers.

Implications for cancer prevention & control

In practice, anti-smoking PSAs vary in their use of smoking cues and scenes and in the strength of the arguments they use. Smoking urges are *increased* when smoking cues occur in the presence of weak anti-smoking arguments. Understanding when and how to employ smoking cues can enhance the effective design of cancer prevention messages.

Saint Louis University

Center for Cultural Cancer Communication

Our focus

Populations disproportionately affected by cancer have less exposure to cancer information and seldom is the information they receive designed specifically for them. Research conducted at the Saint Louis University CECCR is guided by the assumption that information and communication can help eliminate cancer disparities if we *increase its relevance* and *expand its reach* to diverse populations, especially African Americans. Our Center contributes to the National Cancer Institute's (NCI's) goal of eliminating cancer death and suffering by identifying strategies and understanding mechanisms of effect that increase relevance and expand reach of cancer information in African American populations.

Our primary studies

In Study 1, we examine effects of African American women breast cancer survivors' stories on use of mammography among other African American women. The dominant paradigm in cancer communication involves didactic and expository approaches – providing people with health facts and presenting arguments or reasons why they should take a certain action. This approach runs counter to the way people communicate in their daily lives, which is through stories or narrative

communication. Phase 1 of this study is completed and has identified active ingredients of breast cancer survivors' stories that positively affect viewers' engagement in a story, cognitive activity, and similarity to, trust and liking of the survivor. These findings were used to select 70 video clips (from over 1,600) that are included in a final intervention video being tested in Phase 2, a randomized controlled trial comparing narrative to non-narrative cancer communication videos.

In Study 2, we explore the largely untapped potential of cancer communication through Black newspapers. In a community-randomized trial in 24 U.S. cities, we track all cancer coverage in Black and mainstream newspapers, assess population awareness of cancer coverage in a panel survey of 786 Black newspaper readers in the 24 cities, and seek to increase the amount and quality of coverage by providing community-specific cancer news releases to Black newspapers in 12 of the cities. We established the Ozioma ("Good News" in Ebu) News Service to create and distribute the cancer news releases, which are customized with local and race-specific cancer data, census data, and a range of community characteristics and cancer resources. If found to be effective, this approach has great potential to expand the reach of cancer information to

African Americans through 188 Black newspapers in the United States with a combined readership over 6 million.

In Study 3, we test the effects of three different approaches to cultural appropriateness in cancer communication to promote colorectal cancer screening in African American men and women. The Institute of Medicine (IOM) report, *Health Communication Strategies for Diverse Populations*, called for rigorous studies that compare different diversity strategies. In our past research, we identified commonly used strategies to enhance cultural appropriateness of health information including *peripheral* (using pictures and other images of the target group), *evidential* (providing statistical evidence that shows how a problem affect the group), and *sociocultural* (integrating health information in the context of cultural norms, values and beliefs) approaches. This ongoing randomized trial compares these approaches on affective, cognitive, and behavioral (CRC screening) outcomes.

Other CECCR studies

In addition to the primary studies described above, our CECCR has carefully selected and funded eight pilot research projects in cancer communication and has successfully competed for external funding to support many new projects within our CECCR.

Among the CECCR-funded studies, investigators are:

- Identifying affective and behavioral responses to cancer disparity information framed as negative ("Blacks doing worse than others"), neutral ("Cancer affects Blacks") or positive ("Blacks making progress");

- Assessing biophysiological responses to breast cancer survivor stories among African American women and linking them to self-reported cognitive and affective responses;

- Determining the effectiveness of a youth magazine to increase interest in cancer-related careers among low-income African American students at St. Louis City public schools; and,

- Developing and testing the feasibility and effectiveness of a tablet PC-based touch screen interactive multimedia system that provides newly diagnosed African American breast cancer patients with videos clips on treatment and survivorship from African American survivors.

Among the new projects funded from outside the CECCR award, investigators are:

- Evaluating the dissemination and use of an evidence-based breast cancer communication program among African American, Bosnian, and Hispanic women in six community settings;

- Using GIS analysis to examine distance traveled by users of a cancer computer kiosk from home to different community settings in order to identify venues for cancer communication;

- Identifying and understanding factors that influence African American men's reactions to information about prostate cancer screening;

- Testing effects of new and sustainable strategies to increase use of NCI's Cancer Information Service among African Americans and Hispanics; and,

- Training community partners how to select and use evidence-based cancer prevention and control interventions.

Career development for young investigators and those new to cancer communication

Our CECCR is helping to increase the number and quality of cancer communication scientists by providing seed grants, pilot grants, junior faculty career development awards, investigator roles on CECCR studies, a monthly cancer communication seminar series with national presenters, and workshops on methodological and research productivity issues important to cancer communication research. Direct support has been provided to pre- and post-doctoral fellows and junior faculty from three institutions (Saint Louis University, Washington University, University of Missouri) across a wide range of disciplines (communication, epidemiology, anthropology, journalism, nursing, community and family medicine, and internal medicine).

Key partnerships and collaborations

Our CECCR has two major institutional partners, the School of Journalism at the University of Missouri and the NCI-designated Alvin J. Siteman Cancer Center at Washington University. We also work closely with NCI's Cancer Information Service (Heartland Region) and the national Cancer Prevention and Control Research Network. Our Center led the NCI National Working Group on Narrative Cancer Communication Research, resulting in a new model of narrative effects across the cancer control continuum, to be published in *Annals of Behavioral Medicine*.

Primary Project:
Cultural Tailoring for Cancer Prevention and Control in African American Women

Problem

Disparities in cancer incidence and mortality persist between African American women and other groups of women. Cancer communication that leads to increased prevention and screening behaviors may help reduce these disparities.

What we know

It is widely assumed that cancer communication is more effective when it is culturally appropriate for a given population. However, the 2002 Institute of Medicine Report, *Assessing Health Communication Strategies for Diverse Populations*, concluded "there is little evidence available as to whether diversity strategies contribute to success."

Research question

Will cancer information tailored on cultural values of spirituality, family, racial pride, and time orientation increase African American women's use of mammography and intake of fruits and vegetables (FV)?

Disciplines involved

Cultural anthropology, health communication, behavioral science.

Methods

In a randomized trial, 1,227 lower income African American women from 10 urban public health centers were assigned to a usual care control group or to receive a series of six women's health magazines with information tailored to each individual (see Figure 1).

By random assignment, these magazines were generated from either behavioral construct tailoring (i.e., stage of readiness, barriers, self-efficacy; BCT), culturally-relevant tailoring (CRT) or both (BCT+CRT). An 18-month follow-up (72% retention) assessed changes in use of mammography (among women ≥ 40) and FV intake (among women < 40).

Figure 1. "Reflections of You" articles

Figure 2. Getting a mammogram 18-month follow-up (n=192)

% Women 40+ reporting mammogram in last 12 months

| Control | BCT | CRT | BCT + CRT |
| 54.5 | 64.6 | 63.6 | 75.6 |
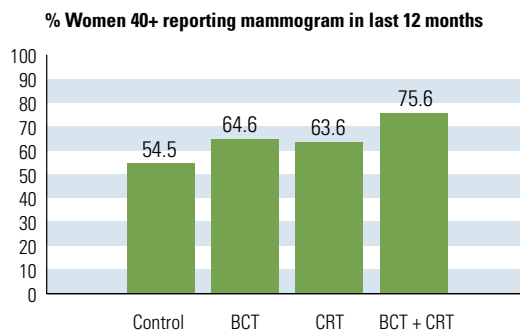
Figure 3. Fruit and vegetable consumption 18-month follow-up (n=599)

Women < 40 years, mean change in FV servings per day

| Control | BCT | CRT | BCT + CRT |
| 0.59 | 0.43 | 0.25 | 0.96 |
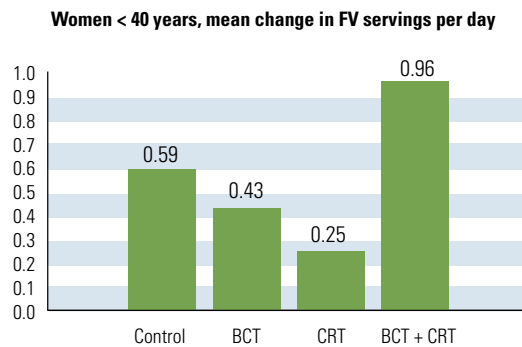
Findings

Women who received BCT+CRT magazines were more likely than those in other groups to report getting a mammogram and had greater increases in daily FV servings consumed (see Figures 2 and 3).

Implications for cancer prevention & control

Cancer information presented in the context of cultural values and beliefs can enhances effect of behavioral construct tailoring in diverse populations.

Next steps

Adapt this evidence-based approach for broader dissemination in African American communities (reference subsequent projects).

Primary Project:

Using Computer Kiosks for Breast Cancer Education in Six Community Settings

Problem

How can effective computer-based cancer control interventions benefit African American communities with high cancer risk but limited access to technology?

What we know

Many populations disproportionately affected by cancer also have limited access to technology. African American, low-income, and low education households are underrepresented among Internet users but express strong interest in gaining access. The Pew Internet and American Life Project recommends increasing public access computing.

Research question

What are the patterns of use and characteristics of users of a breast cancer education computer kiosk for African American women when placed in community settings?

Disciplines involved

Health communication, behavioral science, computer science, geospatial analysis.

Methods

A touch-screen kiosk (Figure 1) was developed from Reflections of You, a proven cancer control program for African American women. The kiosk generates and prints a tailored magazine for each user based on their answers to up to 24 questions. Kiosk use and user characteristics are tracked in an ongoing observational usage study.

Results

Kiosks have been used 10,996 times in 77 community venues from 2003-06. Use is highest in laundromats and lowest in beauty salons (Figure 2).

Figure 1. Touch-screen kiosk
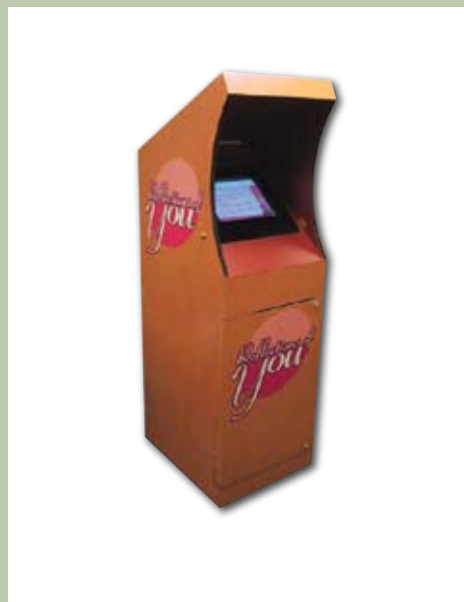
Figure 2. Mean use per kiosk day, by setting

Implications for cancer prevention & control

Laundromats have high rates of kiosk use and high user need for breast cancer information, and serve a significantly more localized population. As cancer surveillance data are increasingly geo-coded, GIS findings like these can inform outreach and clinical trial recruitment strategies.

Next steps

Kiosks have been developed in Spanish and Bosnian languages and are in use now.

Selected publication

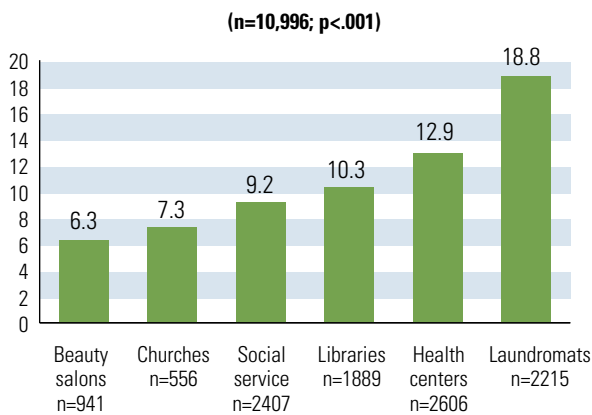Kreuter, M.W., Black, W.J., Friend, L., Booker, A.C., Klump, P., Bobra, S., & Holt, C.L. (2006) Use of computer kiosks for breast cancer education in five community settings. *Health Education and Behavior, 33*(5) 1-18.

Users in laundromats have the lowest breast cancer and mammography knowledge scores (3.8 correct answers to 8 questions) and lowest rates of mammography among women 40+ (48% ever; 31% current); distance from users' homes to where they used the kiosk is shortest for laundromats and libraries and longest for beauty salons and churches (Table 1).

Table 1. Mean distance in miles from user's home to location where kiosk was used, by community setting (all p's < .05 between subsets)	
Community setting	**Miles**
Libraries	2.11
Laundromats	2.35
Social service organizations	3.59
Health centers	4.08
Beauty salons	5.04
Churches	5.71

Primary Project:

Using Survivor Stories to Enhance the Effectiveness of Breast Cancer Communication

Problem

Inconsistent or non-use of mammography among African American women contributes to excess breast cancer mortality. Mammography messages that are meaningful, memorable, motivating, and created by and for African American women may help.

What we know

Experience-based knowledge and communication through storytelling are deeply rooted in the culture of African American women. Research and theory suggest stories may have distinctive capabilities to overcome resistance to cancer-related behaviors and messages, and facilitate processing of cancer information, at least among some groups.

Research question

Is breast cancer information that is presented in personal experience narratives from African American breast cancer survivors more effective than the same information presented in didactic and expository ways in promoting use of mammography among African American women?

Disciplines involved

Narrative communication, behavioral science, anthropology, epistemology, video production.

Methods

We recorded 50 hours of broadcast quality video of 49 African American women breast cancer survivors and family members. Their stories were segmented into 1,624 distinct video clips by topic and coded for narrative quality. In Phase 1 of the study, 300 video clips about breast cancer risk and mammography were viewed by 200 very low-income African American women from neighborhoods with elevated rates of late-stage breast cancer diagnosis. We assessed their engagement in the video, judgments of trust, expertise, and liking of the survivor, and perceived similarity to the survivor.

Results

The most consistent predictor of positive reactions to videos was "ways of knowing," the relative value a woman places on personal experience vs. formal education as sources of knowledge. As women increasingly valued personal experience, they were more engaged in the videos and rated the survivors higher on trust, liking, and expertise (all p's < .05). Having a lower income and fewer years of education also predicted greater trust, expertise, liking, and similarity to the survivor (p's < .05). Certain story characteristics enhanced these effects. When survivors in the videos showed emotion, participants liked them more; when survivors used concrete language (i.e., that aids imagery), participants were more engaged (see Figures 1 to 3).

Figures 1-3. **Survivor narratives: Breast cancer survivors share health information and personal experiences on video**

Implications for cancer prevention & control

Survivor stories may be especially well received by the most socioeconomically disadvantaged populations. Some story characteristics enhance these effects.

Next steps

Phase 2, a three-group randomized trial to begin in late 2006, will test effects of narrative vs. didactic videos on African American women's use of mammography.

Selected publications

Kreuter, M.W., Green M.C., Cappella, J.N., Slater, M.D., Wise, M.E., Storey, D., Clark, E.M., O'Keefe, D.J., Erwin, D.O., Holmes, K., Hinyard, .LJ., Houston, T., & Woolley, S. (in press). Narrative communication in cancer prevention and control: A framework to guide research and application. *Annals of Behavioral Medicine*.

Hinyard, L.J., & Kreuter M.W. (in press). Using narrative communication as a tool for health behavior change: A conceptual, theoretical and empirical overview. *Health Education and Behavior*.

Pilot Project:

Ozioma News Service: Increasing Quantity and Quality of Cancer Coverage in Black Newspapers

Problem

There are 188 Black newspapers in the United States with a combined readership over 6 million but currently no systematic efforts to provide them with race- and community-specific cancer information.

What we know

Black newspapers are a trusted and important source of health information for African Americans.

Research questions

How do Black newspapers cover cancer? Can a news service that provides localized, race-specific cancer stories change the amount and quality of cancer coverage in Black news-papers? Do changes in coverage affect Black newspaper readers' cancer-related knowledge, attitudes, beliefs, and behaviors?

Disciplines involved

Health communication, journalism, media relations, behavioral science.

Methods

In a community-randomized trial in 24 U.S. cities, Black newspapers in half the cities are assigned to receive localized, race-specific news releases and half serve as controls. Releases are created and distributed by the Ozioma ("good news" in Ebu) News Service, a joint effort with the University of Missouri School of Journalism developed specifically for this study. Changes in cancer coverage in intervention vs. control and Black vs. main-stream newspapers are assessed, as are chang-es in cancer awareness, beliefs, and behaviors among 800 readers of these papers in an an-nual panel survey conducted in all 24 cities.

Figure 1.   Release from Ozioma News Service used to develop story published in Black newspaper
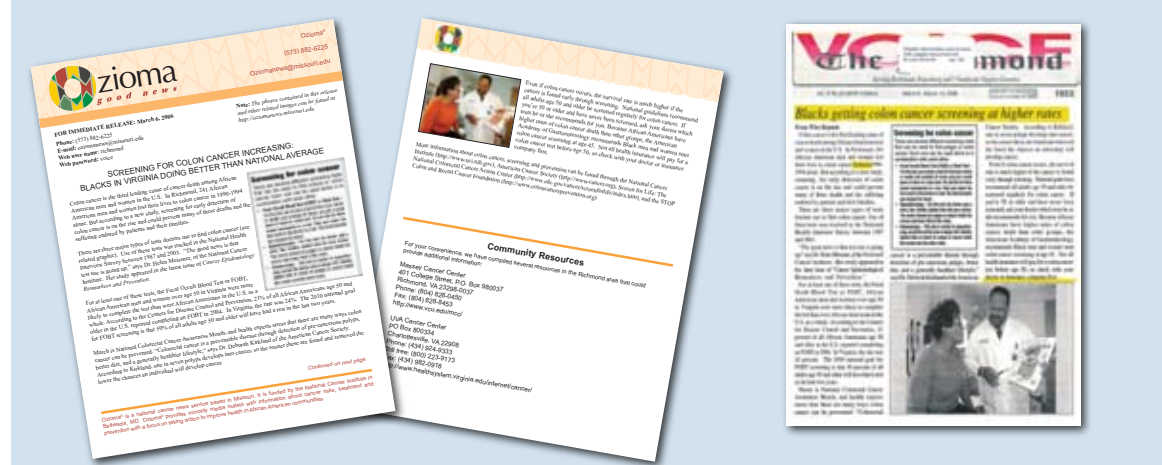
Table 1. Content analysis - coverage of health and cancer in Black newspapers baseline content analysis (n = 6.904 stories)

Variable	Black papers (%)	Mainstream papers (%)	p
Cancer stories	14	10	<.001
Disparity information	32	11	<.001
Community mobilization	17	5	<.001
Personal behavior mobilization	45	16	<.001
NCI as primary data source	9	6	.099
Localized information	40	24	<.001

Results

As a proportion of total health coverage, Black newspapers contain more cancer stories than mainstream newspapers in the same cities.

Stories in Black newspapers are more likely than mainstream newspapers to include a disparity angle, mobilization information, and localization (all p's < .001). To date, 15 localized news releases have been sent to the 12 intervention newspapers, resulting in 9 different newspapers running 39 total stories. These newspapers have a combined circulation of 249,000.

By the numbers – as of September 9, 2006	
Releases sent	**16**
Different newspapers have used the releases	**9**
Total stories printed	**46**
Potential audience of newspaper readers	**249,000**

Implications for cancer prevention & control

With their unique reach, credibility, and influence in many African American communities and demonstrated willingness to cover localized cancer news, Black newspapers are an important channel for cancer communication.

Next steps

If found to be effective, the Ozioma News Service could be offered to all Black newspapers nationally, adopted by NCI's Office of Communication, and adapted for use by other Black and special population newspapers and media.

Pilot Project:

Cultural Targeting Strategies for Colorectal Cancer Communication with African Americans

Problem

The 2002 Institute of Medicine report on Health Communication Strategies for Diverse Populations called for research that would identify and compare effects of different strategies to address the health information needs of diverse populations.

What we know

Our past research and that of others has identified several commonly used strategies to increase the cultural appropriateness of health information for diverse populations, including *peripheral* (using pictures and other images of the target group), *evidential* (providing statistical evidence that shows how a problem affect the group), and *sociocultural* (integrating health information in the context of cultural norms, values and beliefs) approaches.

Research question

How do colorectal cancer communications using peripheral, evidential, and sociocultural approaches to cultural appropriateness differ in their effects on cognitive, affective, and behavioral (screening, diet) outcomes in African American men and women?

Disciplines involved

Cultural anthropology, health communication, behavioral science, nutrition and dietetics, medicine, graphic design.

Methods

In a pilot study leading to the efficacy trial now underway, we assessed reactions to printed colorectal cancer information that used varying combinations of peripheral (P), evidential (E), and sociocultural (SC) approaches to cultural appropriateness. Sixty African Americans (30 men) ages 45 and older with no history of colorectal cancer each read eight randomly ordered, gender-specific, text-only articles using E or SC approaches ($n = 30$) or the same articles with text+P images ($n = 30$). Cognitive and affective responses were measured post-exposure.

Figure 1. **Colorectal cancer information sheets: Sociocultural (upper left) and evidential (lower right) approaches to cultural appropriateness are compared for effect**

Figure 3.   Mean score for cognitive processing

Mean score

5.48 — Evidential
4.96 — Socialcultural
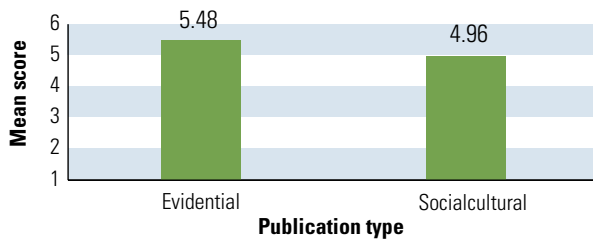
Publication type

Figure 4.   Mean score for cultural appropriateness

Mean score

3.58 — Evidential
4.03 — Socialcultural
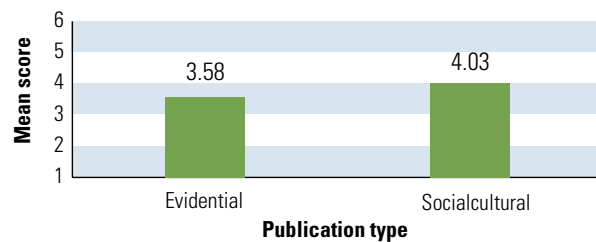
Publication type

**Figure 5.   Cultural appropriateness of graphics:
            pubication by gender**

Mean score

Evidential: Male 3.13, Female 0.87
Socialcultural: Male 1.8, Female 3.45

Publication type

■ Male   ■ Female
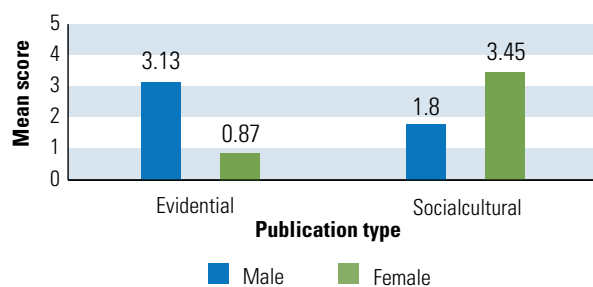
Results

As hypothesized, cognitive processing tended to be greater in response to E materials and perceptions of cultural appropriateness slightly higher when SC was used (Figures 3 and 4). Men and women differed in perceptions of cultural appropriateness of materials that included P images; men preferred the E text and women preferred SC text (Figure 5).

Implications for cancer prevention & control

Targeted cancer communication for African Americans may require a balance of evidential and sociocultural strategies, with different materials for men and women.

Next steps

We are currently recruiting 820 African American men and women for a randomized efficacy trial to determine how cancer communication using P, E, and SC approaches affect colorectal cancer screening and diet.

Pilot Project:

Behavioral and Emotional Responses to Cancer Disparity Messages Among African Americans

Problem

Little is known about how African Americans process negatively framed messages about cancer disparities (e.g., "Blacks are worse off than Whites").

What we know

Such framing of disparity information is commonplace among physicians, health care organizations, researchers, and especially news media. Behavior change theories suggest that disparity messages like these might lead African Americans to perceive themselves as "at risk" and, therefore, increase their motivation to make risk-reducing changes.

Research question

How do emotional and behavioral intention responses to a news article on colorectal cancer and screening differ when the same content is framed as positive, negative, or neutral in a sample of African American men and women?

Disciplines involved

Health communication, behavioral science, journalism.

Methods

In a double-blind randomized study, 300 African American men and women were assigned to read one of four mock news articles reporting identical epidemiological data on colorectal cancer mortality and screening. Articles reported this information in one of four ways: emphasizing current rates among African Americans (neutral); emphasizing disparities in current rates between African Americans and Caucasians (negative; Figure 1); empha-

sizing improvements among African Americans over the past 20 years (positive; Figure 2); and emphasizing disparities in the rate of improvement between African Americans and Caucasians over the past 20 years (negative).
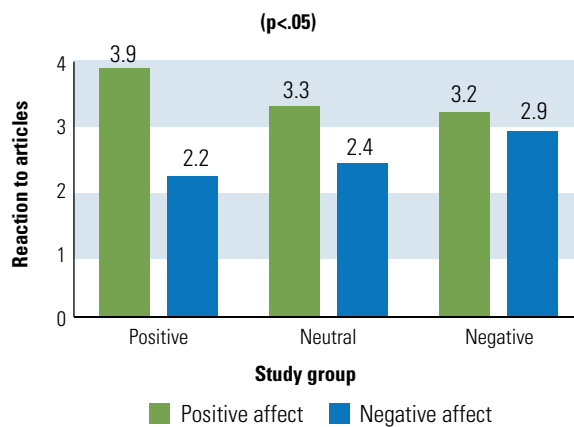

Figure 1. Example of negative article emphasizing disparities in current rates between African Americans and Caucasians

Figure 2. Example of positive article emphasizing improvements among African Americans over past 20 years

Figure 3. Reactions to articles -
positive and negative affect (p<.05)

(p<.05)

Reaction to articles

- 3.9 — Positive (Positive affect)
- 2.2 — Positive (Negative affect)
- 3.3 — Neutral (Positive affect)
- 2.4 — Neutral (Negative affect)
- 3.2 — Negative (Positive affect)
- 2.9 — Negative (Negative affect)

Study group

■ Positive affect ■ Negative affect

Figure 4. "I want to be screened for colon cancer
so I will know if I have it"

(1=SD. 5=SA, p<.05)

Desire to be screened

- 4.79 — Positive (Low mistrust)
- 4.55 — Positive (High mistrust)
- 4.63 — Neutral (Low mistrust)
- 4 — Neutral (High mistrust)
- 4.63 — Negative (Low mistrust)
- 3.48 — Negative (High mistrust)

Study group

■ Low mistrust ■ High mistrust
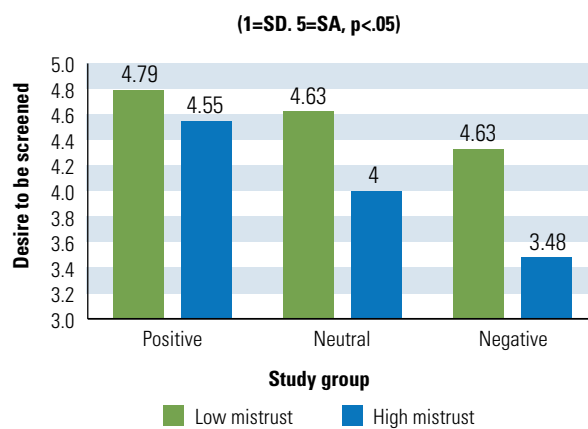
Results

Those reading the positively framed article reported more positive and fewer negative emotions and a greater desire to be screened for colon cancer than those reading a negatively framed article (Figures 3 and 4).

As participants' positive affect increased and negative affect decreased, their perceived benefits of screening and desire to be screened increased and perceived barriers to screening decreased. Those who read the negatively framed story and had high levels of mistrust at pre-test were the least likely to want to be screened (Figure 4).

Implications for cancer control & prevention

Use of negatively framed disparity communication may actually undermine efforts to reduce cancer disparities.

Next steps

Evaluate effects of positively framed messages on cancer screening.

University of Wisconsin

Technology Enhancing Cancer Communication Center

The problem

Recent research has yielded extensive information about how best to treat and reduce the suffering from cancer. The challenge is to apply this valuable knowledge quickly and effectively to the real-world needs of cancer patients and family caregivers. Otherwise both patients and their families (important partners in the fight against cancer) suffer more than necessary. Unfortunately, resource constraints and system failures make it difficult for healthcare providers to deliver the information and support that patients and families need.

Enormous investments are being made to enhance the potential of informatics to meet that need. However, significant improvements in discovery, development, and delivery are needed before channels (such as the Internet) approach their potential for cancer communication. Without this research, the gap will continue to widen between the potential of informatics and the way in which they are actually being used.

Our focus

The Wisconsin CECCR is discovering, developing, testing, and delivering evidence-based interactive cancer communication systems that improve the quality of life for cancer patients and their families.

We perform the following:

- Develop practical, cost-effective ways for cancer communication systems to meet the needs of cancer patients and their families, with a particular emphasis on the underserved;

- Develop next-generation cancer communication systems that dramatically improve quality of life by taking full advantage of recent innovations in communications technologies;

- Understand the cancer communication system mechanisms of effect;

- Investigate how patients and their caregivers use new communication devices most effectively;

- Explore the most appropriate ways to accommodate a range of learning, coping, and information-seeking styles;

- Develop a structure that facilitates collaborative research with a greater impact than is possible through individual research grants; and

- Widely disseminate research discoveries and technological developments to patients, researchers, vendors, and healthcare providers.

We have established unique and innovative partnerships with the National Cancer Institute's (NCI) Transdisciplinary Tobacco Use Research Centers (TTURC) and the Cancer Information Service, the University of Wisconsin's Comprehensive Cancer Center, the University of Texas' MD Anderson Cancer Center, the Dana-Farber Cancer Institute, Tufts-New England Medical Center, the Hartford Hospital Cancer Program, Alvin J. Siteman Cancer Center at Barnes-Jewish Hospital, the Washington University School of Medicine, and the Southwest Georgia Cancer Coalition Disparities Center.

Properly developed and delivered, information technology can support cancer care by providing patients and their family caregivers with:

- Up-to-date, timely, and accurate information tailored to their needs;

- Convenient ways for those who may otherwise feel isolated from the support they desperately need to contact peers and clinicians who are able to provide the needed support;

- Ready access to training in key skills and important feedback from the health-care team; and

- Resources to make more informed, better cancer-related decisions (treatment selection, clinical trial participation, whether to enter hospice, etc.).

We serve a wide range of cancer patients and family caregivers, from those who face early stage cancer to those who face imminent death. While our Center emphasizes randomized trials, we engage in development and dissemination functions, including research on how best to sustain interventions and integrate interactive cancer communication systems into communities and health organizations. For instance, we are extending our research on barriers to the diffusion of information technology (supported by the Agency for Healthcare Research and Quality) and a Digital Divide Project (supported by NCI and the Markle Foundation) to improve the delivery and impact of interactive cancer communication systems to low-income populations.

The Center of Excellence grant allows us to conduct research that would not be possible through individual R01s.

The Wisconsin Center of Excellence in Cancer Communication Research Center has three theme areas, each including at least one R01 research project and other initiatives.

Optimizing the use of family and clinical resources

This area develops and tests the impact of a communication system that trains and links family caregivers to the clinical team to help patients with advanced cancers.

Three R01s are involved. The first, funded through the Center of Excellence grant, examines a communication system's impact on patients with advanced lung cancer and their families. The second, funded by National Institute of Nursing Research tests the value of a system that collects and reports information to the clinical team about the status and concerns of advanced breast and prostate cancer patients and family caregivers. The third and newest NCI-funded R01, in partnership with Tufts University-New England Medical Center, will develop and test an integrated, interactive cancer communication system to improve the quality of life for families of children undergoing and recovering from bone marrow transplants.

Understanding what interactive cancer communication systems work and why

The interactive cancer communication systems used in this research has been shown in several randomized control trials to improve quality of life. It is clear that these systems work, but it is less clear how and for whom they work best.

This theme area includes one randomized control trial, several studies examining how different types of use influence outcomes, and a project to develop a theoretical framework to help explain the mechanism of effect. The intent is to provide a framework for development and delivery of future interactive cancer communication systems.

Tailoring treatment

This area uses two R01s plus several smaller experiments to explore whether an interactive cancer communication system can improve the coordination of human resources. We are exploring a dynamic linkage of a human cancer information specialist with an interactive cancer communication system to produce a system in which these two reinforce one another. Next, we are designing and testing programs that employ knowledge about the user to tailor information provided and encourage more effective use of the system. This is important when programs contain many services and extensive information. For instance, our breast cancer communication system offers 15 services and content equivalent to a 1,000-page book.

Wisconsin's Center of Excellence has expanded substantially beyond its original three randomized control trials and pilot studies. We added three new randomized trials and several other studies (e.g., the creation of a Spanish-language version of the breast cancer communication system and the dissemination of a smoking cessation program developed jointly with the Wisconsin TTURC). We are disseminating the services developed, building a strong theory base, and expanding collaborations (as mentioned above) in ways that would not have been possible without the resources of the Center of Excellence in Cancer Communication.

Building the pool of cancer communication researchers

The Center offers a weekly cancer communications research seminar, summer programs for high school and undergraduate students, and pre- and post-doctoral training and has produced researchers and faculty in cancer communication.

Interdisciplinary activities

We benefit from a strong partnership between a wide array of disciplines. In addition to medical, surgical, and radiation oncologists, and nurses and social workers, the team includes adult learning specialists, communication scientists, systems engineers, decision and management scientists, clinical psychologists, family theorists, biostatisticians, educational psychologists, graphic artists, and computer and media experts.

New research studies generated by Wisconsin CECCR

CECCR

- **Bone marrow transplant families**
  Tufts-New England Medical Center (NEMC)
- **Caregivers**
  National Institute of Nursing Research (NINR)
- **Assets**
  National Institute on Aging (NIA)
- **New technologies**
  Robert Woods Johnson Foundation (RWJF)
- **Disseminate smoking program**
- **Develop/disseminate Spanish-language version**

Primary Project:

Understanding How Interactive Cancer Communication Systems Work and for Whom

Problem

A breast cancer diagnosis can dramatically affect a woman's quality of life, social support, and ability to cope. In the last 20 years, there has been a proliferation of interactive cancer communication systems designed for cancer patients. Unfortunately, because of a lack of well controlled, systematic research, communications systems are currently based more on common sense and intuition than on sound evidence. Some services have not been shown to help and may even distract patients from using helpful features. As a consequence, thousands of cancer patients and their families may be receiving suboptimal help in their struggle with cancer. There is clear evidence that these communications systems will help cancer patients. The University of Wisconsin Center of Excellence in Cancer Communication Research has focused on how to identify the most helpful types and combinations of services and whether particular types of patients (e.g., underserved, depressed) benefit from particular services. The results of this work should help designers develop more effective communication systems.

What we know

A randomized trial[1] assigned recently diagnosed breast cancer patients to:

1. Standard care;

2. Access to and training in Internet with links to high quality breast cancer sites ("Internet" condition); or

3. Access to and training in a Comprehensive Health Enhancement Support Systems' (CHESS) interactive communication system with comprehensive information, and emotional and decision support.

Quality of life (QOL) was monitored for 9 months, but computers were left in the home for 5 months.

The Components Study, an R01

Developing superior interactive cancer communication systems requires a better understanding of what types of services are most effective, how they work, and for whom they work. As medical resources and dollars become increasingly scarce, this research can inform the delivery of cost-effective care on a population-wide basis.

Research question

The questions here are what are the effects on quality of life and health care utilization of different types of cancer communication services when used alone or in combination:
(a) information services,
(b) information + social support services, and
(c) information + social support + interactive learning services.

Secondary analyses *will discover* the mechanisms by which service combinations work and who benefits most from these services.

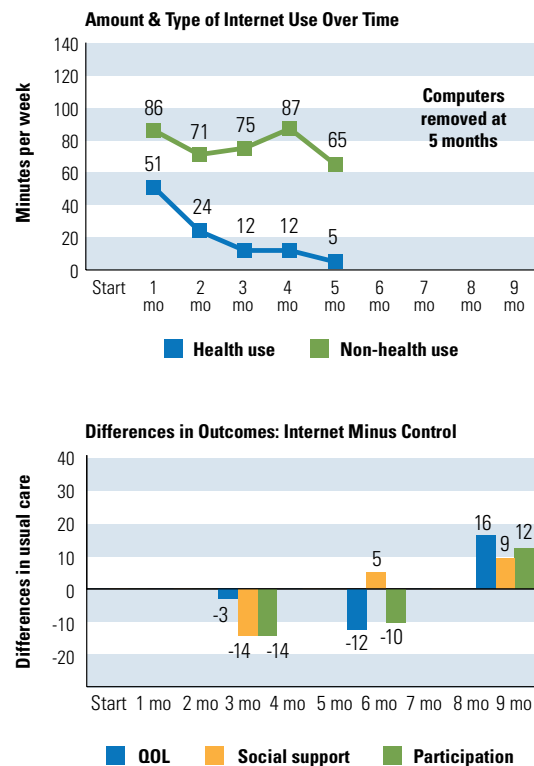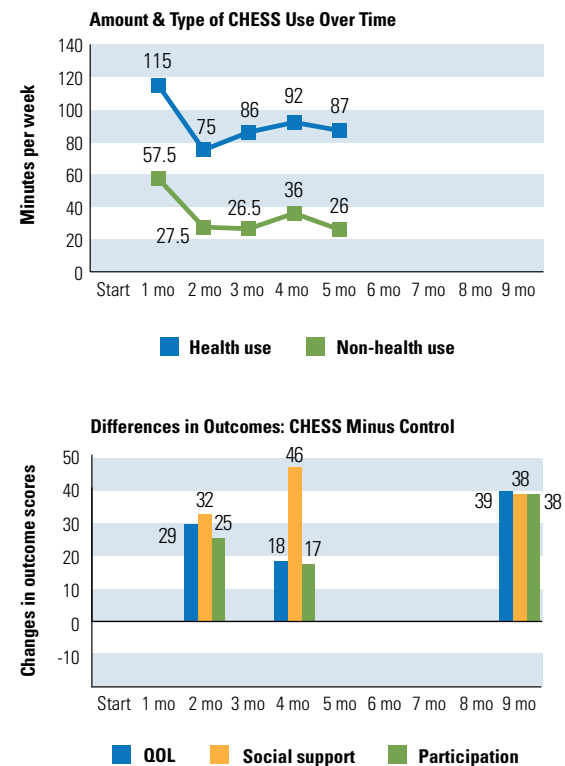## Figure 1. Internet group's use of nonhealth web sites

Amount & Type of Internet Use Over Time

Computers removed at 5 months

Health use values: Start 51, 1 mo 24, 2 mo 12, 3 mo 12, 4 mo 5

Non-health use values: 1 mo 86, 2 mo 71, 3 mo 75, 4 mo 87, 5 mo 65

Minutes per week

■ Health use   ■ Non-health use

Differences in Outcomes: Internet Minus Control

Differences in usual care

Values: -3, -14, -14, -12, -10, 5, 16, 9, 12

■ QOL   ■ Social support   ■ Participation

Figure 2. CHESS group's use of health web sites

Amount & Type of CHESS Use Over Time

Health use values: Start 115, 2 mo 75, 3 mo 86, 4 mo 92, 5 mo 87

Non-health use values: Start 57.5, 1 mo 27.5, 2 mo 26.5, 4 mo 36, 5 mo 26

Minutes per week

■ Health use   ■ Non-health use

Differences in Outcomes: CHESS Minus Control

Changes in outcome scores

Values: 29, 32, 25, 18, 46, 17, 39, 38, 38

■ QOL   ■ Social support   ■ Participation

The top left chart (Figure 1) shows that over time the Internet group's use of nonhealth web sites was relatively stable, while use of health web sites rapidly dropped off and was consistently less than nonhealth sites. Figure 2 shows that the CHESS Group use of health web sites, including CHESS, consistently exceeded use of nonhealth web sites. Figure 1 shows that the Internet group, compared to control did not significantly improve on quality of life, social support, and participation in health care at 2-, 4- and 9-month assessments. Figure 2 demonstrates that the CHESS had better outcomes over controls across time. All outcomes at 9 months, two of three at 2 months, and one of three at 4 months were statistically significant (p<.05). These data clearly show that patients used and benefit from the CHESS communication system. The evidence does not, however, reveal the types of services that produce benefit or which types of patients need which types of services.

Methods

Newly-diagnosed breast cancer patients (N=360) are being randomly assigned to one of four intervention groups in a stacked design: (a) information only, (b) information and social support services only, (c) information + social support + interactive learning tools, or (d) a usual breast cancer care control. Patients complete surveys at pre-test and 5 post-tests ending at month 13 (intervention removed at month 6). In accordance with Consolidated Standards of Reporting Trials (CONSORT) criteria, primary data analysis will begin when the data are fully collected.

Understanding How Interactive Cancer Communication Systems Work and for Whom, *continued*
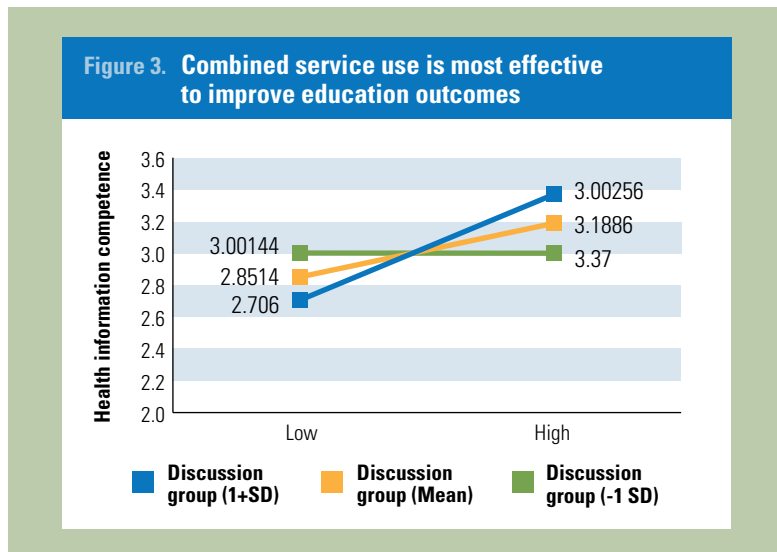
What we are learning

Recent analyses of previously funded research

- Correlational analyses have revealed that patients who receive information services in combination with support groups and other interactive services are the most likely to feel they have the information they need to cope with their illness (Figure 3). Hence, information-only cancer communication systems are probably not optimal.[2]

- Previous research indicated that many breast cancer patients participate in online support groups, but few studies have demonstrated quantifiable effects from participation. New Wisconsin Center of Excellence research demonstrates that participation does contribute to emotional health benefits and that one mechanism for these effects appears to come from having the opportunity to talk openly and constructively about living with breast cancer independent of actually receiving support from others.[3]

Implications for cancer prevention & control

Understanding the mechanisms by which different services benefit different types of patients will improve the ability to personalize interactive cancer communication systems to reduce cancer-related suffering, improve quality of life, and increase participation in health care.

Figure 3. Combined service use is most effective to improve education outcomes

Health information competence

- Discussion group (1+SD): 2.706 (Low) → 3.00256 (High)
- Discussion group (Mean): 2.8514 (Low) → 3.1886 (High)
- Discussion group (-1 SD): 3.00144 (Low) → 3.37 (High)

Next steps

■ Complete Components Randomized Control Trial and analyze data in accordance with CONSORT criteria after the data are collected. Disseminate findings.

■ Map use patterns to patient characteristics: disease stage, life situation, socioeconomic subgroups using data from several CHESS studies to better allocate services to specific types of patients.

■ Develop and test electronic games to inform, educate, and support patients and their extended family system.

Selected publications

1. Gustafson, D., Hawkins, R., Pingree, S., McTavish, F., Shaw, B., Chen, W., Vorathongchai, K., Stengle, W., & Stewart, J. Internet-based interactive support for cancer patients: Are integrated systems better? Submitted to the *Journal of General Internal Medicine*.

2. Shaw, B., Han, J.Y., Baker, T., Witherly, J., Hawkins, R., McTavish, F., & Gustafson, D. (in press). How women with breast cancer learn using interactive cancer communication systems. *Health Education Research*.

3. Shaw, B., Hawkins, R.P., McTavish, F., Pingree, S., & Gustafson, D. (2006). Effects of insightful disclosure within computer mediated support groups on women with breast cancer. *Health Communication, 19,* 133-142.

University of Wisconsin

Improving the Timing and Value of Information and Support for Cancer Patients Over the Course of the Disease

Problem

Cancer treatments are increasingly customized to improve patient outcomes. Conversely, information and educational material for cancer patients is typically generic. By contrast, psycho-oncology services delivered face-to-face by professionals are tailored to the individuals' informational and psycho-social needs as they evolve over the treatment trajectory. Such services are expensive and not available to many patients.

Interactive cancer communication systems hold great promise for personalizing and delivering timely information and psycho-social support to cancer patients. Yet little is known about the variables upon which to tailor and the benefits of tailoring via a computer or by human communication.

What we know

Tailored information is more effective than generic cancer information in promoting primary cancer prevention behaviors, such as smoking, dietary fat reduction, and cancer screening. Yet to be investigated are the effects of tailoring to address the information and psychosocial needs of patients diagnosed with cancer. We know that consulting with a Cancer Information Specialist satisfies immediate information needs and validates cancer-related decisions. Little is known about whether and how such experts can help patients cope across the post-cancer diagnosis continuum.

Cancer information mentor randomized clinical trial

Primary research question

What are the relative effects of periodic, proactive telephone consultations with a Cancer Information Mentor, a tailored interactive cancer communication system, or a combined Cancer Information Mentor and tailored interactive cancer communication system on quality of life for newly diagnosed breast cancer patients?

Secondary analyses

What are the most effective ways for an interactive cancer communication system to deliver personalized, relevant, and timely information and support? What are the most effective ways for a Cancer Information Mentor to improve psychosocial outcomes?

Methods

Using a 2x2 design, 360 recently diagnosed breast cancer patients are being randomly assigned (Internet only vs. the Comprehensive Health Enhancement Support Systems' [CHESS]; Cancer Information Mentor or not). CHESS is personalized to patient-reported treatment schedule and concerns, while providing access to the full content (Figure 1).

Figure 1. **Example of a personalized Comprehensive Health Enhancement Support System web site**
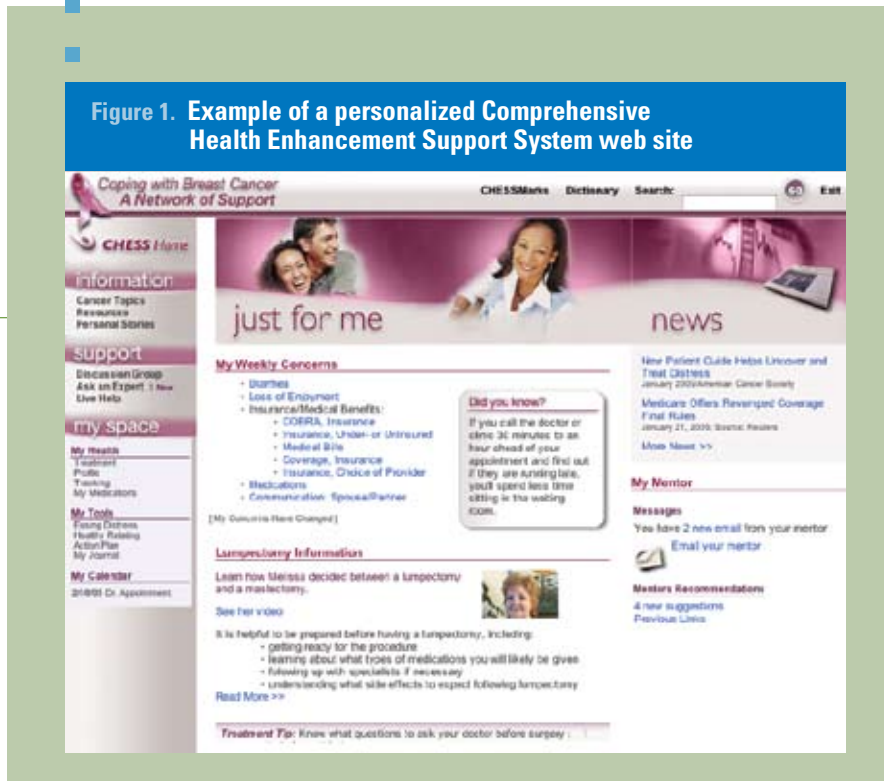
The Mentor (derived from the Cancer Information Specialist's role) personalizes the experience by guiding the patient's information seeking, use, and interpretation via 10 scheduled phone conversations over the 6-month intervention. The Mentor + CHESS condition integrates and reinforces the two services. Outcomes are assessed longitudinally using six surveys from pre-test through 13 months along with computer use data. In accordance with Consolidated Standards of Reporting Trials (CONSORT) guidelines, primary analyses will begin after all data are collected.

What we are learning

With the randomized control trial about half-completed, several early insights are emerging from our CECCR data. It appears that the ongoing relationship with the Mentor focuses the patients' information seeking. Perhaps most importantly, the personalized Comprehensive Health Enhancement Support System – when combined with the Mentor – directs patients to use the most interactive, demanding, and perhaps the most beneficial features of CHESS, such as cognitive-behavioral therapy, relationship training, action planning, and journaling.

While we collect data for our randomized controlled trial, several insights are emerging from ongoing Center of Excellence-funded work. A review article summarizing data sets from a number of previous controlled clinical trials has examined how underserved cancer patients have used and benefited from the use of the CHESS system. Correlational analyses indicate that underserved African Americans used the interactive, tailored services more than their more privileged Caucasian counterparts, which is a likely explanation for the greater effects from CHESS use in the underserved population. This finding validates our direction in developing the more powerful and personalized interactive tools that are being tested in our current controlled clinical trial.[1]
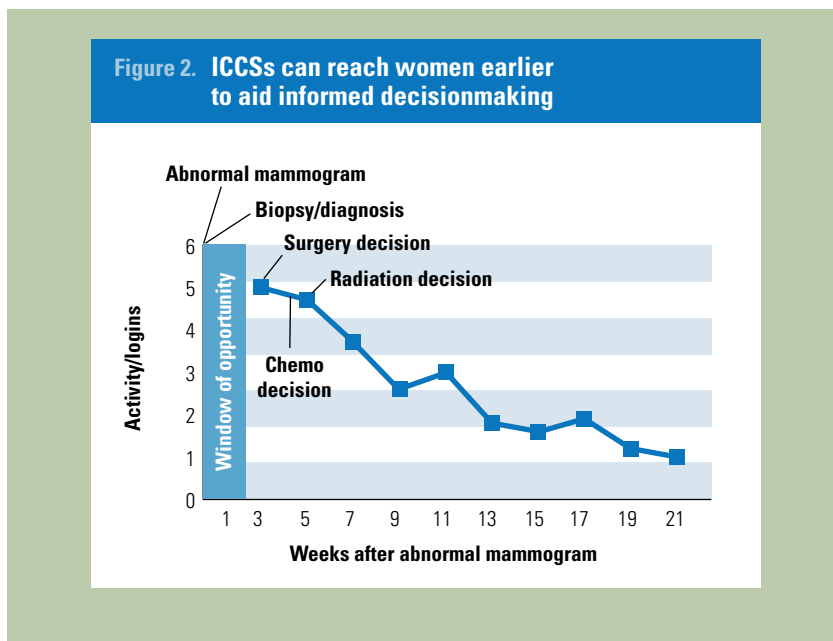
Primary Project:

Improving the Timing and Value of Information and Support for Cancer Patients Over the Course of the Disease, *continued*

Exciting new research holds the promise to improve the delivery of information and support for women throughout the process of breast cancer diagnosis. We have developed a probabilistic model that harnesses an artificial intelligence technique called a Bayesian Network to accurately predict breast cancer risk using imaging findings and demographic information. This technique, being translated to clinical practice, has the potential to provide a new opportunity for providing a breast cancer communication system to women determined by mammography to be at high risk (Figure 2). This system could potentially help them plan for the possibility of a cancer diagnosis with the goal of reducing distress and facilitating shared decisionmaking immediately following diagnosis.[2]

Our researchers are advancing the health informatics and cancer communication fields with conceptual models about the factors that influence the success of cancer communication systems. The focus is on tailoring content to users, increasing patient engagement in decisionmaking, and amplifying the systems' sense of 'presence' through integrating interactive programs that are more responsive to users and extend opportunities for peer and expert support.[3]

Figure 2. ICCSs can reach women earlier to aid informed decisionmaking

Abnormal mammogram
Biopsy/diagnosis
Surgery decision
Radiation decision
Chemo decision
Window of opportunity
Activity/logins
Weeks after abnormal mammogram

Implications for cancer prevention & control

■ Cancer patients need information and support that evolves with them over the course of their illness.

■ More interactive services (vs. generic cancer information) combined with human support offer the potential to improve quality of care for cancer patients.

Next steps

■ Complete Mentor Study primary and secondary analyses in accordance with CONSORT guidelines.

■ Complete a randomized control trial, recently funded by NCI, to determine whether the results from this breast cancer study extend to prostate cancer patients.

■ Disseminate findings.

Selected publications

1. Shaw, B., Gustafson, D., Hawkins, R., McTavish, F., McDowell, H., Pingree, S., & Ballard, D. (2006). How underserved breast cancer patients use and benefit from eHealth programs: Implications for closing the digital divide. *American Behavioral Scientist, 49*, 823-834.

2. Burnside, E.S., Rubin, D.L., Shachter, R.D., Fine, J.P., & Leung, W. (in press). Using a Bayesian network to predict breast cancer risk for microcalcifications on mammography in order to reduce benign breast biopsies. *Radiology.*

3. Walther, J.B., Pingree, S., Hawkins, R.P., & Buller, D.B. (2005). Attributes of interactive online health information systems. *Journal of Medical Internet Research, 7* (3), 1-10.

Primary Project

Building Continuity in Care: Supporting the Patient Facing Advanced Cancer, Their Family Caregiver, and Clinical Team

Problem

Cancer inflicts great suffering on patients and their families. Many facing advanced cancer lack the knowledge, skills, or resources to make appropriate decisions. The clinical team's ability to help control cancer-related distress is limited by patients' reluctance to communicate with clinicians between visits about their physical and psychosocial concerns. Integrating the patient, caregiver, and clinical team is essential. New ways to foster efficient communication and relationships are needed.

What we know

With recent advances in treatment, cancer has evolved from an acute to a chronic disease. Paradoxically, a lengthened survival time can extend patient suffering and erode family caregivers' economic, physical, and emotional well-being. Fostering family caregiver competence, confidence, and emotional well-being is essential to maximizing the patient's ability to cope with advanced cancer. Several randomized trials have consistently shown that breast cancer patients use and benefit from our Comprehensive Health Enhancement Support Systems (CHESS) – an interactive cancer communication system with comprehensive, accurate information, interactive learning tools, and support. Despite the benefits, little is known about whether systems like CHESS can improve the well-being of advanced cancer patients and their family caregivers, and/or facilitate communication between patients, caregivers, and the clinical team.

The Clinician Integration Study, an R01

The Clinician Integration randomized control trial aims to develop and evaluate an empirically based interactive cancer communication system to address end-of-life issues facing the patient and the family caregiver, and facilitate communication with the clinical team.

Primary research question

This project studies the effects on the negative affect of family members caring for patients with advanced lung cancer of an interactive cancer communication system that provides:

- Palliative care information and support for patients and caregivers; and

- Communication tools that report to the clinical team about the patient's status from the perspectives of both the patient and caregiver.

Secondary analyses will investigate specific effects of the clinician report system and the palliative care content on how patients and family caregivers cope across the illness trajectory, and on caregiver bereavement.

Methods

A total of 252 advanced-stage lung cancer patients and their primary informal caregiver are randomized to a (1) Internet control group; or (2) treatment group receiving CHESS with the Clinician Report System

Figure 1. Example of Comprehensive Health Enhancement Support System with the Clinician Report System web page for treatment group with advanced-stage lung cancer patients and primary informal caregiver

Figure 2. Caregivers' heightened depression and anxiety
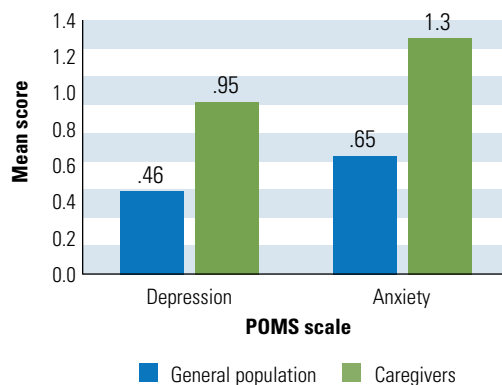
(Figure 1). In order to discover the long-term effect of the ICCS, patient-caregiver dyads remain on study for 25 months and complete bi-monthly surveys. Caregivers continue on study for up to 13 months after the patient dies and complete seven surveys. Two clinic visits are audiotaped and surveys of physician and patient visit satisfaction are completed for communication analyses. In accordance with CONSORT guidelines, primary analyses will begin after all data are collected.

What we are learning

Preliminary analyses of Clinician Integration Study pre-tests

Patients and caregivers are suffering.

- Patients experience many distressing symptoms, yet caregivers rate the patient's distress higher than patients rate their own distress.

- Thirty-five percent of caregivers lack confidence to meet patient needs.

- Caregivers have higher rates of anxiety and depression than the general population (Figure 2), thus limiting their ability to function effectively in their caregiving role.

Building Continuity in Care: Supporting the Patient Facing Advanced Cancer, Their Family Caregiver, and the Clinical Team, *continued*

Caregiver needs assessment

■ Caregivers' information needs vary across the patients' cancer trajectory and into bereavement (Figure 3). Most studies of patient needs treat them as static across the cancer trajectory. The development of interactive cancer communication systems should be based on the discovery of how those needs change over time and across cancer-related events.

Recent analyses from prior studies

■ High-quality cancer information enhances the doctor-patient relationship.[2] An interactive communication system that provides high quality, readily accessible, easy to understand information improves the patient's relationships with the clinical team.

■ There is a complex relationship between the patient and caregiver and the impact on caregiver effectiveness. For instance, analyses of pre-test data from the current randomized trial find that if the patient is depressed but the relationship with the family caregiver is open and positive, the caregiver is less likely to be depressed and more likely to play their caregiving role effectively than if the relationship is poor. Hence our emphasis in new development focuses on those things a communication system can do to improve family relationships and explains why we have a family studies researcher on our team.

Implications for cancer prevention & control

■ Caregivers need information and support that is specifically relevant to where the patient is in the disease trajectory.

■ Interactive cancer communication systems can enhance relationships with the clinical team.

■ Providing communication tools to improve family relationships may improve caregiver effectiveness.

Next steps

■ Complete Clinician Integration Study analyses in accordance with CONSORT guidelines.

■ Disseminate findings.

Selected future research aims

■ Develop a communication system to support families of children receiving bone marrow transplant and evaluate effects on quality of life in randomized trial. (NCI-funded R01 to Tufts-New England Medical Center).

■ Develop and test a hospice decision aid for cancer patients, family, and clinician (R21 proposal for October 1, 2006).

■ Examine couples communication at end of life (funded by the Fetzer Foundation).

■ Develop and evaluate an online Life Review Legacy intervention integrated with a telephone counselor (feasibility study funded by a University of Wisconsin Comprehensive Cancer Center Aging and Cancer P20, R21 to be submitted October 1, 2006).

Selected publications

1. Shaw, B., Hawkins, R., Arora, N., McTavish, F., Pingree, S., & Gustafson, D. (2006). An exploratory study of predictors of participation in a computer support group for women with breast cancer. *CIN: Computers, Informatics, Nursing, 24*, 18-27

2. Shaw, B., Han, J.Y., Hawkins, R.P., Stewart, J., McTavish, F., & Gustafson, D. (in press). Doctor-patient relationship as motivation and outcome: Examining uses of an interactive cancer communication system. *International Journal of Medical Informatics*.

Figure 3. **Changing caregiver needs across cancer trajectory**

Legend:
- Disease/medical
- Caregiving
- Caregiver well-being
- Financial/legal
- Spirituality
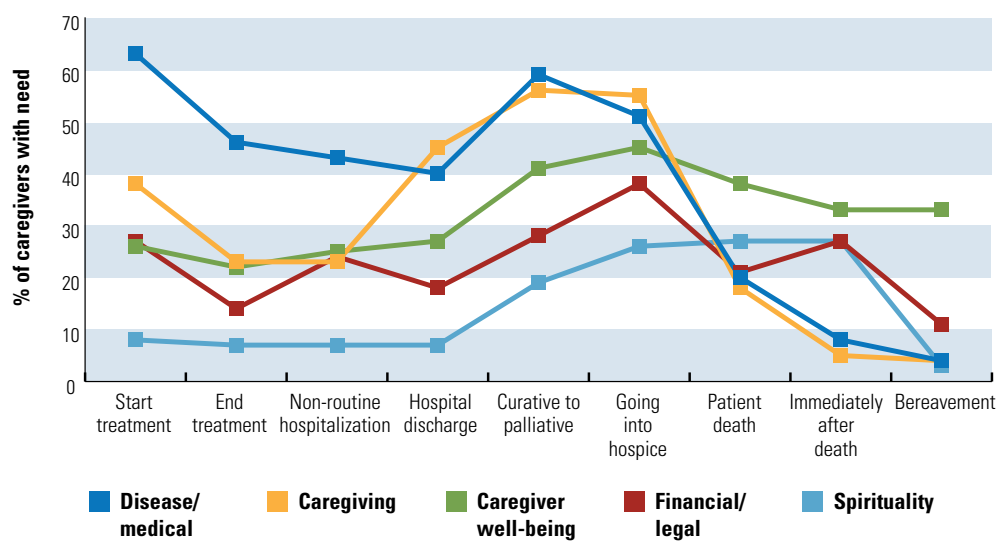
CECCR Productivity

CECCR-generated Pilot and Spin-off Projects

University of Michigan

Forever Free – Experimentation and Analysis Strategies for Time-Varying Treatment Components in Cancer Prevention
Principal Investigator: Susan A. Murphy, PhD

Eat for Life Psychometric Pilot – Cultural and Motivational Dietary Message Tailoring
Principal Investigator: Kenneth A. Resnicow, PhD

THeME Non-responders – Design of Effective Web Data Collection for Cancer Prevention Studies
Principal Investigator: Mick P. Couper, PhD

Stepping Up to Health – Automated Step-Count Feedback to Promote Physical Activity in Chronic Disease
Principal Investigator: Caroline R. Richardson, MD

Web Scatter – Understanding Information Scatter on the Internet
Principal Investigator: Suresh K. Bhavnani, PhD

CSATS – Cancer Screening Adherence Through Technology-Enhanced Shared Decision Making
Principal Investigator: Masahito Jimbo, MD, PhD, MPH

Decider Guider – Development of a Preference-Tailored Intervention for Increasing Colorectal Cancer Screening
Principal Investigator: Sarah T. Hawley, PhD, MPH

fMRI – An fMRI Study of Tailored Health Messages Related to Smoking Cessation
Principal Investigator: Hannah Faye Chua, PhD

CECCR-generated Pilot and Spin-off Projects

University of Pennsylvania

Sociocultural Impact of Media Coverage of Genetic Risks of Smoking
Principal Investigators: Chanita Hughes-Halbert, PhD, and Oscar Gandy Jr., PhD

Content Analysis of TV Direct-to-Consumer Advertising of Prescription Drugs
Principal Investigator: Dominick Frosch, PhD

Cancer-Related Information Seeking and Scanning Behaviors among Vietnamese Immigrants
Principal Investigator: Giang Nguyen, MD

Transportation and Visual-Verbal Redundancy in Anti-Smoking Advertisements
Principal Investigators: Melanie Green, PhD, and Joseph Cappella, PhD

Functional MRI of Brain Response to Anti-Smoking Advertising
Principal Investigator: Daniel Langleben, MD

Cancer Mass Media Communication About Survival and Death
Principal Investigator: Jessica Fishman, PhD

Exploring Individual Eye Movement Patterns When Viewing Smoking Cessation Public Service Announcements
Principal Investigator: Deborah Linebarger, PhD

Public Attitudes Towards and Intentions to Receive a Vaccine for Human Papilloma Virus (HPV)
Investigators: Amy Leader, M.P.H., Judith Weiner, PhD, Stacy Gray, MD, MaP, Bridget Kelly, PhD Candidate, Joseph Cappella, PhD, Robert Hornik, PhD

The Impact of Smoking Cues in Anti-smoking Public Service Announcements on Smoking Urge, Message Processing and Intention to Quit Smoking
Principal Investigator: Yahui Kang, PhD Candidate

Antismoking Public Service Announcement Evaluation Study
Principal Investigator: Yahui Kang PhD Candidate

Effects of Advertisement Manipulations on Smokers False Inferences About Quest Cigarettes
Principal Investigator: Andrew Strasser, PhD

Effects of Threat-Oriented and Efficacy-oriented Antismoking Ads on Adult Smokers' Attitudes and Beliefs about Quitting, and Intentions to Quit
Principal Investigator: Norman C. H. Wong, PhD
Co-investigator: Joseph N. Cappella, PhD

University of Pennsylvania

Interest in Direct to Consumer Sales for BRCA 1 and BRCA 2 Mutation Testing Among Women with a Family History of Cancer
Principal Investigator: Stacy Gray, MD, MaP
Co-investigators: Katrina Armstrong, MD, and Robert Hornik, PhD

Testing the Effects of Highly Person-Centered Messages in an Online Breast Cancer Support System
Principal Investigator: Alyssa Klein, PhD Candidate

The Nature of Risk Perception and Cancer Screening and Prevention Among African-Americans
Principal Investigator: Oscar Gandy, PhD

Testing Anxiety vs. Health Anxiety: The Consequences for Screening Adherence
Principal Investigator: Barbara Kahn, PhD

Analyses of the Intention-behavior Relationship
Principal Investigator: Martin Fishbein, PhD

Investigating the Role of the Willingness Construct in Predicting Smoking (including quitting) Behaviors
Principal Investigator: Martin Fishbein, PhD

Investigating the Role of Injunctive and Descriptive Norms as Determinants of Cancer-Related Behaviors
Principal Investigator: Martin Fishbein, PhD
Co-Principal Investigator: Aaron Smith-McLallen, PhD

Differences in How the Theory of Planned Behavior Predicts Intentions for Cancer Prevention and Screening Behaviors Among Racial Subgroups
Principal Investigator: Aaron Smith-McLallen, PhD
Co-Principal Investigator: Martin Fishbein, PhD

Social Support and Linguistic Analysis Software
Principal Investigators: Alyssa Klein, PhD Candidate, and Lee Humphreys, PhD Candidate

Effects of Message Frames Emphasizing Personal Versus Family or Societal Benefits on Engaging in Health Behaviors (Including Vaccination for HPV)
Principal Investigator: Bridget Kelly, PhD Candidate

Effects of Knowledge of Persuasive Intent on Children's Ability to Resist High Calorie Food Advertising
Principal Investigator: Ariel Chernin, PhD Candidate

CECCR-generated Pilot and Spin-off Projects

Saint Louis University

An Understanding of Breast Cancer Beliefs and Mammography Use Among Thai Women in the United States
Principal Investigator: Suwattana Kumsuk, PhD candidate

Meaning in Health Disparity Messages Project
Principal Investigator: Elisia Cohen, PhD

The Influence of Cancer Disparity Message Valence on Cognitive and Emotional Responses and Intention to be Screened
Principal Investigator: Rob Nicholson, PhD

Comparing Reactions to Narrative vs. Non-narrative Breast Cancer Survivor Videos
Principal Investigator: Leslie Hinyard, MS

Pre-production Testing of Colorectal Cancer Screening Publications
Principal Investigator: Wai Hsien Cheah, PhD

Cognitive and Emotional Effects of Cancer Survivor Testimonies
Principal Investigator: Glenn Leshner, PhD

Pathways to Health Professions: Magazine for Minority Middle School Students
Principal Investigator: Kassandra Alcaraz, MPH candidate

Providing Culturally-Appropriate Psychosocial Support and Education to African American Breast Cancer Patients Through the Personal Narratives of Survivors
Principal Investigator: Mark Walker, PhD

CECCR-generated Pilot and Spin-off Projects

University of Wisconsin

Effects of Interactive Cancer Communication System Use on Quality of Life of Breast Cancer Patients and Simulation Modeling of Level of Use
Principal Investigator: David Gustafson, PhD

Latent Curve Analysis of Breast Cancer Use Data
Principal Investigator: David Gustafson, PhD

Analysis of Doctor-Patient Interactions
Principal Investigator: David Gustafson, PhD

Modeling CHESS Effects on Breast Cancer Patients' Emotional Well-being
Principal Investigator: Robert Hawkins, PhD

Social Network Structures in an Online Discussion Group
Principal Investigator: Robert Hawkins, PhD

Why Do Patients Use the Internet? The Effects of Insufficiency on Patients' Health-related Internet Use
Principal Investigator: Robert Hawkins, PhD

Who Uses CHESS for What? Cancer-related Information Seeking Within an Interactive Cancer Communication System
Principal Investigator: Robert Hawkins, PhD

Effects of Tailoring on Message Processing Modes
Principal Investigator: Suzanne Pingree, PhD

Online Discussion Groups: Does Active Engagement Make a Difference in Quality of Life Outcomes?
Principal Investigator: Suzanne Pingree, PhD

Breast Cancer Patients Preferences for Algorithms and Standard Left Menus
Principal Investigator: Suzanne Pingree, PhD

Effects of Target, Topic, and Time on Disclosure in an Online Breast Cancer Support Group
Principal Investigator: Suzanne Pingree, PhD

Does Person-centeredness Make a Difference in Online Breast Cancer Support Groups?
Principal Investigator: Suzanne Pingree, PhD

University of Wisconsin

Health Benefits of Communicative Participation in Online Breast Cancer Support Groups
Principal Investigator: Suzanne Pingree, PhD

Interplay of Emotion and Self-efficacy
Principal Investigator: Suzanne Pingree, PhD

Online Social Interaction Among Cancer Patients
Principal Investigator: Linda Roberts, PhD

Optimizing Interface Design of Inline Support Groups to Improve Delivery of Online Support for Colorectal Cancer Patients
Principal Investigator: Bret Shaw, PhD

Predictors of Online Info-Seeking Related to NCI CIS Research Agenda
Principal Investigator: Bret Shaw, PhD

Exploring Cancer Patients' Receptivity to the Next Generation of Online Support Communities
Principal Investigator: Bret Shaw, PhD

Doctor-Patient Relationship as Predictor and Outcome of ICCS Use
Principal Investigator: Bret Shaw, PhD

International and Intercultural Issues in e-Health
Principal Investigator: Bret Shaw, PhD

Relationship Between Coping Styles and Uses of CHESS Services
Principal Investigator: Bret Shaw, PhD

Effects of Prayer in Online Support Groups
Principal Investigator: Bret Shaw, PhD

Optimal Service Use to Maximize Learning from an ICCS
Principal Investigator: Bret Shaw, PhD

Online Narrative Interventions for Aging Cancer Patients
Principal Investigator: Meg Wise, PhD

Legacy Storytelling Online for Improving Quality of Life of Palliative Care Receipts and Caregivers
Principal Investigator: Meg Wise, PhD

CECCR-generated Publications

University of Michigan

Armstrong, K., Weber, B., Ubel, P. A., Peters, N., Holmes, J., & Schwartz, J. S. (2005). Individualized survival curves improve satisfaction with cancer risk management decisions in women with BRCA1/2 mutations. *Journal of Clinical Oncology, 23,* 9319-9328.

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University of Michigan

Fagerlin, A., Zikmund-Fisher, B. J., Ubel, P. A., & Smith, D. M. (2003). Measuring numeracy when people hate math tests. *Medical Decision Making, 23,* 560.

Fagerlin, A., Zikmund-Fisher, B. J., & Ubel, P. A. (2005). How making a risk estimate can change the feel of that risk: shifting attitudes toward breast cancer risk in a general public survey. *Patient Education and Counseling, 57,* 294-299.

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CECCR-generated Publications

University of Pennsylvania

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Frosch, D., Krueger, P., Hornik, R., Cronholm, P., & Barg, F. (2007). Creating demand for prescription drugs: a content analysis of television direct to consumer advertising (in press). *Annals of Family Medicine.*

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University of Pennsylvania

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University of Pennsylvania

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CECCR-generated Publications

Saint Louis University

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Saint Louis University

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Saint Louis University

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Saint Louis University

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