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Extending the Reach, Effectiveness, and Efficiency of Communication: Evidence from the Centers of Excellence in Cancer Communication Research

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1. An Extraordinary Opportunity

At the turn of the century, the U.S.-based National Cancer Institute (NCI) included a section in its annual budget proposal identifying “cancer communications as an area of “extraordinary opportunity” for investment in scientific understanding [1]. At the time of this announcement, the World Wide Web was barely 7 years old, yet communication scientists had already begun documenting an unprecedented amount of Web traffic going to health-related sites. A Harris Poll conducted in 1998 found that 54 million Americans had gone online looking for health information, with cancer showing up as the third most commonly searched health term after “depression” and “allergies” [2]. Moreover, physicians and patient educators were beginning to notice that patients were engaging health information in new ways. Some patients would come into their clinical appointments loaded with information culled from their searches of the Web; others were feeling overwhelmed and were not sure how to take advantage of the largely unreadable, highly technical scientific content they found online [2–6].

The world of communication technology was changing dramatically and rapidly [7]. What NCI recognized is that with change comes opportunity. By tracking these changes directly and by investing in cutting-edge science that would allow researchers to harness the power of the new information technologies, NCI leaders reasoned that it should be possible to make productive, scientific inroads into the “new frontier.” Just as the Gutenberg revolution in movable type altered the world of science and health over five centuries ago, the new revolution in communication technology was beginning to herald a new opportunity for extending the reach, effectiveness, and efficiency of cancer communication activities [8].

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1.1. Propitious Timing

Timing of the “extraordinary opportunity” was propitious. In the early 1990s, population scientists began tracking the very first downturn in age-adjusted deaths from cancer in the United States for over a century [9]. Much of this success in the war on cancer could be attributed to the concomitant downturn 20 years earlier in the number of Americans addicted to tobacco products. Decreases in lung and bronchus cancer led the charge in a much-welcomed respite from the heretofore increasing burden of the disease. Other victories were observed with decreases in mortality from colorectal, breast, cervical, and prostate cancer as illustrated in Figure 1 [10].

What makes these successes distinct is that they cannot be attributed to improvements in treatment alone. They also reflect the contributions of efforts emphasizing prevention and early detection.

In the fee-for-service medical care environment of the United States, it is often all too easy to respond reactively to manifest symptoms, and, by frequently engaging the healthcare system late in the process, more-extensive tissue damage and the ravaging effects of late-stage disease are too often unavoidable. Where the medicine of the new century needs to go is to become predictive, personalized, and preemptive [11]. Patient communication and education efforts, both at the individual and population levels, will be needed to ensure the public is in a position to take full advantage of the new advances in predictive and preemptive medicine [12]. For example, in March of 2000, the celebrity host of the *Today Show*, Katie Couric, dedicated airtime to the topic of colorectal cancer screening, a topic that was near to the celebrity after losing her husband to colon cancer in 1998. Public health researchers in the United States were able to track significant increases in the use of colonoscopy after following temporal trends in two different data sets. The researchers termed this broad public health impact of a celebrity-endorsed public awareness campaign the *Katie Couric* effect [13].

The importance of effective communication with patients as the lifeblood of a self-improving medical system was also becoming apparent. In 1999, the Institute of Medicine (IOM) released a report titled “*To Err is Human: Building a Safer Health System*” [14]. The purpose of the report was to track the etiology of a rash of medical errors that collectively accounts for up to 98,000 deaths per year in the United States. The authors of the report conducted a systematic review of the causes of human error within systems of care and came to the conclusion that most of the identified errors could have been thwarted by building a better culture of safety within the healthcare delivery system. They pointed to errors in communication as a prime target for amelioration.

In 2001, the IOM followed up with a consensus report entitled “*Crossing the Quality Chasm: A New Health System for the 21st Century*” [15]. Its purpose was to focus health systems researchers on six goals for redesigning delivery systems nationwide. The goals included making a system that was (a) safe, (b) effective, (c) patient-centered, (d) timely, (e) efficient, and (f) equitable. To achieve these goals, the report’s authors laid out a series of guiding rules. Many of them had to do with creating a system that did a better job of supporting patients’ communication needs proactively across the continuum of care. This would imply creating a system that emphasized ongoing “healing relationships” with patients, customizing care to meet patients’ needs and values, putting the patient as the source of control for treatment and prevention decisions, and facilitating the flow of information freely between all members of the care team both on the provider side (i.e., physicians, nurses, office staff) and the patient side (i.e., patients, families, care givers). Improved patient-centered communication would be at the center of the redesign efforts.

Following release of the 2001 report, policy makers and health systems planners recognized that care in the fragmented mosaic of services in the United States was not being served by the same levels of modernization in communication and information technology as in the other sectors. As President Barack Obama quipped in a 2009 address to the American Medical Association, “we do a better job in this country of tracking a FedEx package than we do tracking people’s medical records.” In response to the IOM recommendations, President George W. Bush established an Office of the National Coordinator for Health Information Technology to coordinate a massive modernization effort for information and communication technology within healthcare. In 2009, President Obama and the 111th Congress accelerated diffusion of connective health information technologies by allocating resources and setting incentives for the “meaningful use” of health information technology through passage of the Health Information Technology for Economic and Clinical Health Act (Title XIII of the American Recovery and Reinvestment Act) [16].

1.2. Health Communication and Informatics Research

Investment in communication and informatics technologies alone would not be sufficient for improving the quality of healthcare and public health outreach in systematic ways [17]. What would be needed is an understanding of how technologies could be made to support human predilections and capacities in more effective ways. “Despite a strong commitment to delivering quality healthcare,” explained authors of a report subsequently published by the National Research Council, “persistent problems involving medical errors and ineffective treatment continue to plague the industry. What is needed is a re-balancing of investments in health information technology “to place a greater emphasis on providing cognitive support for health care providers, patients, and family caregivers” [18].

It is in this context that the National Cancer Institute founded the Health Communication and Informatics Research Branch [8]. The branch was created to make strategic investments in the transdisciplinary science needed to generate new, evidence-based supports for effective health communication in an era of exploding technological capacity. The branch was organized following the principles of cancer control and prevention outlined by Hiatt and Rimer, and founded upon programs gaining traction in Canada [9]. It uses a surveillance mechanism—a biennial general population survey called the Health Information National Trends Survey, or HINTS—to keep track of shifts in the information ecology and to monitor the effectiveness of cancer communication programs [19]. It also invests in fundamental research in communication and informatics, intervention research, and application/program delivery. In conjunction with its partners in NCI’s Office of Communications and Education, it routinely engages in efforts to synthesize the evidence emerging from its investments and to disseminate the findings to health practitioners. This dedicated issue of Patient, Education, and Counseling is one example of these synthesis efforts.

2. The Centers of Excellence in Cancer Communication Research (CECCRs)

One of the flagship investments of the Health Communication and Informatics Research Branch is the Centers of Excellence in Cancer Communication Research, or CECCRs (colloquially pronounced “seekers”), program. The CECCRs program is a P-50 “Centers” grant initiative, funded by the National Institutes of Health. The Center grants represent substantial investments by the government, usually with set-aside moneys to get them started. Each grant is expected to be organized around a group of “Core” administrative and scientific functions, while maintaining an active research program oriented on at least three scientific studies. Moneys are also set aside for “pilot” or “developmental” projects as a way of responding to lessons learned within each 5-year program.

Four 5-year grants were awarded in 2003: one each to (a) the University of Michigan at Ann Arbor, Michigan; (b) the University of Pennsylvania in Philadelphia, Pennsylvania; (c) the University of Wisconsin at Madison, Wisconsin; and (d) St. Louis University in St. Louis, Missouri. Areas of focus ranged from understanding the effects of a changing public health information environment on individual behavior (in the case of the University of Pennsylvania grant) to marshalling the effectiveness of tailored and targeted interventions (in the case of the University of Michigan and St. Louis University grants) to creating a comprehensive health enhancement and support system for medical care (in the case of the University of Wisconsin) grant.

In 2008, the program was renewed for a second round of set-aside funding. Although the spirit and structure of the first round of funding was preserved, NCI requested that applicants focus especially on the implications of their research for clinical settings following the precepts of the previously compiled literature review on Patient Centered Communication [20–22]. Each of the original grantees received funding in the second round, although the Missouri team moved their operations from St. Louis University to Washington University. In addition, NCI was pleased to announce funding for a fifth grant to the Cancer Research Network. The Cancer Research Network is a consortium of researchers situated within a network of health maintenance organizations (HMOs). Given the characteristics of an HMO environment, the new grantee was ideally suited for investigating the clinical implications of patient communication and education research.

2.1. An Emphasis on Translation

At about the same time as the transition from CECCRS I to CECCRS II, NCI began working with health communication partners at the American Cancer Society and the Centers for Disease Control and Prevention to create a translational path for CECCR findings to take them from discovery to practice. Together, the three organizations hosted a program in Atlanta, Georgia in April of 2008 to showcase findings from the CECCR program and to create opportunities for follow-up discussions. Representatives from throughout the U.S. cancer community attended, including individuals from academia, the Lance Armstrong (now “Live Strong”) Foundation, Susan G. Komen for the Cure, the Robert Wood Johnson Foundation, the Ad Council, and others.

One of the “next steps” identified by the conference attendees was to issue a special “call for papers” to the CECCR grantees. The intent would be to capture elements of the emerging science from the initiative within a thematic issue for broad distribution to both the scientific and practitioner communities. The journal of Patient Education and Counseling was chosen as the publication venue: (a) because of its scholarly treatment of communication issues and (b) because of its international reach. Although the United States was the environment in which the research was conducted, the implications transcend borders.

2.2. Content of the Special Issue

The authors of the papers selected for inclusion in this special issue all share a common view. Each one recognizes that rigorous, evidence-based science will be needed to provide health communicators and educators with the tools and frameworks needed to improve individual and population-based health outcomes in the 21st Century. In addition, each embraces the goal articulated by the IOM—to rivet clinical health and public health service delivery to the values and needs of patients. More importantly, the work of the contributors to the special issue provides new insight into the communication revolution as it can be leveraged to improve cancer care.

For example, several articles in the issue focus on the attributes of specific populations. One population, in particular, is a set of African American women who for various reasons are unduly burdened by the effects of late-stage disease. To address the communication needs of this population, researchers began investigating the requirements for adopting an Afrocentric approach. A key principle in taking an Afrocentric approach to inquiry is the concept of “nommo,” which refers to the “generative and productive power of the spoken word” [23]. It stems from an oral cultural tradition where knowledge, attitudes, ideas, and notions toward specific behaviors are made meaningful. This is affirmed in the work relating to narratives described herein by Kreuter and McQueen. In a parallel vein, Sanders-Thompson and her colleagues investigate the contributing roles of an evidential approach, a peripheral approach, and a sociocultural approach on cognitions, attitudes, and behaviors of African American women.

Another population is that group of people who have been “touched” directly or indirectly by cancer. These are people who have experienced first-hand the life-altering reality of a disease that used to be a death sentence but for many can now be controlled with adherence to advanced treatments. These are also people who experienced the realities of the healthcare system first-hand and are in a position to report on what works and doesn’t work in supporting patients’ needs. Hawley and colleagues offer insight into this population by reporting on a survey designed to assess cancer patients’ perceptions of care coordination. Namkoong and colleagues delve deeply into the social and psychological processes operating within breast cancer support groups and illustrate how perceptions of self-efficacy may be moderating effects on emotional well-being. Hawkins reports early results from a randomized clinical trial of components within an eHealth intervention among newly-diagnosed breast cancer patients and offers insight into the mediating processes associated with self-determination, as well as exploring the nuanced implications of the trial’s results.

This period of rapidly changing communication options may well be creating a “convergence” culture in health communication, a phenomenon Jenkins described as the relationship between media convergence, a participatory culture, and a value on collective intelligence [24]. The communications research agenda is contributing to our understanding of the impact of this new culture on health information. The article by Bigman and colleagues addresses the impact of combinations of public approaches with diverse aims on the intention to obtain the HPV vaccine. In this case, industry’s promotion and appeal, advocates’ interpretation and contextualization, and the media’s framing of risks and potential risks all contribute in different ways to the decisional process of consumers. Likewise, Baker and colleagues describe a cross-center effort by a group of leading communication scientists to apply the rigor of CONSORT (Consolidated Standards of Reporting Trials) criteria to the topic of eHealth interventions. They explore the convergence of new media and the evolution of scientific standards for evidence.

Notwithstanding the role of technology in operationalizing the theoretical frameworks of communication, there are still challenging areas in which a more robust understanding of theoretical application remains. One such area is risk communication. The delivery of health information that requires an understanding of data should consider the general tendencies of lay audiences when processing risk information and a tendency to “satisfice,” or make do with incomplete information [25], as well as the emotional effects that cancer or the risks of cancer can generate. Work such as that of Zikmund-Fisher and colleagues remains critical to our capacity to communicate effectively and in a manner that provides our audiences with the knowledge they need to make decisions appropriate for their situations and in the context of their lived experiences. Similarly, the work by DuBenske and her associates explores the role of caregivers as mediators in the relationship between information competence and clinic visit satisfaction.

In the final section of the special issue, we have asked diffusion-of-innovation experts Dearing and Kreuter to speculate on a framework for moving innovations into practice in order to achieve broad-scale impact from evidence-based applications of communication science within the general population. Their article builds on a Push-Pull-Infrastructure Model to organize efforts for building better communication interventions by capitalizing on knowledge of audiences and markets to create a sense of “pull” from those seeking better solutions to personally felt communication needs. The idea of “designing for diffusion” takes on special significance in an emerging information ecology that relies on concepts of “Web 2.0” principles of social connectedness and participation.

3. Looking Ahead

There is likely no better time to be working in the area of health communications. Whether studying it or applying it, we are operating in a time that will likely be looked upon as a “game changer” period in history. On the one hand, the science of communication and behavioral support has advanced to a point in which our theoretical foundations can begin to guide our decisions in communicating lifesaving information to our patients and to the general public. At the same time, we are finally witnessing the fruits of our labors on one of the most intractable health conditions of the past century: cancer. In the early 1990s, after decades of continued escalation in mortality and burden, the curve for cancer mortality began to bend downward. That change in trajectory was led by public health victories in reducing exposure to the carcinogenic influence of tobacco smoke. Throw in the incredible change in capacity brought about by the communication revolution—and our expansion of scientific knowledge to guide our efforts in reaching patients with effective communication strategies should skyrocket.

In this special issue of the Patient Education and Counseling, we have taken advantage of the escalation of effort within NCI to build an evidence base in health communication and informatics so we could bring a sample of research articles to the attention of communication and education specialists. We do this knowing that we have only touched the tip of the iceberg in identifying the trends and techniques that will influence patient communication in the future. Nevertheless, we hope that the work presented in this special issue will at least capture the imagination of the journal’s readers as we all strive to take full advantage of an “extraordinary opportunity” in communication research.

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Figure 1.
Excerpt from the 2010 American Cancer Society publication, “Cancer Facts and Figures,” illustrating how cancer mortality (especially among males) began decreasing in 1993.

Figure 2.
Organization of cancer communication research at the National Cancer Institute following the Canadian model of cancer control.