E-Health as Dialogue: Communication and Quality of Cancer Care

Linda Harris, Connie Dresser*, and Gary L. Kreps**

*National Cancer Institute
Health Communication and Informatics Research Branch
Bethesda, MD 20982
harrisl@mail.nih.gov
dresserc@mail.nih.gov

**George Mason University
Department of Communication
Fairfax, VA 22030
gkrepsg@gmu.edu

Abstract

The communication demands in cancer care are very high, involving gathering, interpreting, and sharing complex and often emotionally-charged information among a network of interdependent caregivers, health care professionals, and patients. Communication technologies (such as interactive computer systems, advanced telecommunications programs, and multimedia educational programs) have been developed, adopted, and adapted to help individuals confronting cancer to meet the unique communication demands of cancer care, to access the most relevant and accurate health information, to coordinate complex interdependent caregiving activities, to gather and provide needed social support, and to facilitate informed decision making. The purpose of this paper is to examine the uses of health communication technologies, often referred to as e-health, to promote needed information sharing, feedback, and dialogue in cancer care.

Overview

The cancer care process is complex and challenging for all involved, especially for patients, for informal caregivers/supporters, and for health care providers. A diagnosis of malignant cancer certainly challenges health care consumers who receive the frightening news to come to grips with the diagnosis and its impact on their lives, as well as to make sense of available treatment options for effectively confronting the disease. Family members and friends of the diagnosed individual are also challenged to make sense of cancer and its many influences on their lives and their personal relationships, so they can provide needed support and help as health care advocates. Health care providers are challenged to gather relevant information to make accurate diagnoses, share information about relevant treatment options, facilitate treatment decision-making, and help coordinate cancer care. Communication is the critically important social process that helps these individuals confronting cancer to make sense of the disease and its impact on their lives, to make relevant cancer care decisions, and to respond effectively across the continuum of cancer care, from cancer prevention, through detection and diagnosis, through cancer treatment and survivorship, even to the end-of-life (Kreps, 2003).

The communication demands in cancer care are very high, involving gathering, interpreting, and sharing complex and often emotionally-charged information among a network of interdependent caregivers, health care professionals, and patients. Communication technologies (such as interactive computer systems, advanced telecommunications programs, and multimedia educational programs) have been developed, adopted, and adapted to help individuals confronting cancer to meet the unique communication demands of cancer care, to access the most relevant and accurate health information, to coordinate complex interdependent caregiving activities, to gather and provide needed social support, and to facilitate informed decision making. The purpose of this paper is to examine the uses of health communication technologies, often referred to as e-health, to support cancer care.

Systemic E-Health Research and Cancer Care Technologies

Scientists working with the Health Communication and Informatics Research Branch at the National Cancer Institute (NCI) have found that systemic e-health research can help guide the use of communication technologies and improve the quality of cancer care. E-health research is conceptualized here as the ongoing interaction of complex adaptive systems in which researcher and subject continually adapt to the other's reciprocal inquiries and feedback. These interactions, when supported with information and communication technologies, can monitor and change the quality of cancer care immediately, automatically and continuously. Following the lead of the Institute of Medicine's systemic model of health care and recommendations for quality improvement, we offer examples from work supported by the NCI in which e-health research is being conducted to improve the quality of cancer care. One of these research programs, conducted

in partnership with the Veterans Health Administration, is designing and implementing an e-health research system to monitor and improve the quality of care for cancer patients receiving chemotherapy; another research program in Multimedia Technology and Health Communication is part of the Small Business Innovation Research initiative that is helping small businesses build feedback into their behavioral health products and interventions. Finally, we discuss the implication of this systems approach to health communication technologies for cancer care research and practices in the 21st century.

Designing for Quality

In 1998 the Committee on the Quality of Health Care in America was constituted to identify strategies for achieving a substantial improvement in the quality health care in the U.S. Its dynamic approach invited health communication scientists to apply systemic theoretical and methodological tools to the study of health care in ways that other models of health care have not. First, the Committee viewed health care as a function of the interactions (including electronic) among its participants, rather than as a static institution. This process model of 'health care as communication' is complementary with a systems view of health communication and suggests exciting new research directions for communication scientists. Second, it based its claims on the contemporary science of complex, adaptive systems rather than on traditional economic or medical models. This science presumes that changes in quality are continuous events that, although not predictable in detail or direction, are highly predictable in their occurrence. Third, the Committee, in perhaps its most radical claim, asserts that improvements in quality will flow from a patient-centered rather than a medical institution-centered system. Finally, it postulates that systems can be designed to improve quality. Its recommendations are made in terms of design changes, specifically, designs driven by patient needs, not the typically suggested changes in provider incentives or payment methods.

In 2001 the Institute of Medicine published the committee's report on the state of the quality of care in the U.S. This report, Crossing the Quality Chasm: A New Health System for the 21st Century, 2001, offers a challenge and a heuristic model for redesigning the health care system to dramatically improve the quality of care. Meanwhile at the National Cancer Institute, health communication scientists in the Health Communication and Informatics Branch have been developing an e-health research methodology that is in many ways complementary to the IOM's approach and recommendations. This chapter describes how these two approaches, from the IOM and from NCI, are aligned and can be used to enhance the use of health communication technologies in cancer care. One area of alignment is the science of complex, adaptive systems, which informs both of our approaches to communication, context and change.

The Science of Complex Adaptive Systems

Over the past 40 years the science of complex, adaptive systems (CAS) has evolved from von Bertalanffy's original systems theory (1968). This contemporary, nterdisciplinary science has a rich history of inquiry, from the human body's immune system (Varela & Coutinho,1991); the mind (Morowitz & Singer, 1995); the stock market (Mandelbrot, 1999); human organizations (Brown & Eisenhardt, 1998) and human communication patterns (Cronen & Pearce,1981). The science of complex, adaptive systems has focus on the interactions inherent in the multiple systems including the Internet's rapid world-wide evolution, to VISA's remarkable self-evolving efficiencies, to the Veterans Health Administration's radical transformation into a sophisticated health care system. A set of defining features of complex adaptive systems has arisen from this research paradigm:
Adaptablity. Learning, creativity and self-change are inherent capabilities of complex adaptive systems;
Interdependence. Systems are interdependent and serve as context for each other;
Synergism. The whole of a system is greater than the sum of its parts. (Plsek, 2001).

According to this model, change and adaptation happen naturally within the context of the relationships among interdependent system agents. Plsek's (2001) model further specifies that one can observe change occurring within the interactions of complex, adaptive systems: "When complex, adaptable systems interact, their actions are interconnected such that one system's actions changes the context for the other system. In complex adaptive systems, change (either creativity or error) is an emergent product of the interaction of two components of the system and is essence of what helps the system organize itself and adapt" (Plsek, Appendix B). In summary, the unit of analysis is the interaction between systems rather than their structure. Creativity and adaptivity can be observed in action.

People as Complex, Adaptive Systems

The study of human communication, being an interdisciplinary science, has multiple theoretical roots. Communication theory, like CAS, has one set of roots in systems theory. Norbert Wiener, the "father" of cybernetics, observed the continuous flow of information. "I approached information theory from the point of departure of the electrical circuit carrying a continuous current" (Wiener, 1956, 23.) The continuous feed back loop-the essence of human communication, was first fundamental to cybernetics, the science of maintaining

order in a system (Campbell, 1960). From within a systemic model of human communication individuals are conceptualized as complex and adaptive and interdependent systems, where each individual's action is feedback for the other's actions and interpretations.

Human communication is also rooted in phenomenological approaches. Rogers (1994), in his history of communication science, traces this influence back to Dewey, Cooley, Park and Mead, who argued that "the individual subjectivity of how a message is perceived is an essentially human quality…thus, to these first four American scholars of communication, how an individual makes sense out of information, and thus how meaning is given to a message, was a fundamental aspect of the communication process". P74.

A number of communication theorists have joined systems theory and phenomenology into communication models that conceptualize humans as complex, adaptive systems, and unique among those systems in their ability to make sense of their actions. "The ability to coordinate, give, and read nonverbal and verbal cues makes humans excellent feedback users," Cragan and Sheilds, (1994). Other communication theorists hold similar views of humans as particularity complex systems, in large part due to their ability to create and change meaning. (Donohew and Ray, 1990; Kreps, (1990). Cronen, Pearce and Harris, (1979) extend this model to propose a systemic view of communication where the source of meaning (or knowledge) is within the interaction of two complex adaptive systems (people). This coordinated creative process is constrained primarily by logical forces (what "makes sense"). Humans, through their interactions, are adapting, creating context for each other and synergistic-all the characteristics of complex, adaptive systems capable of changing the quality of their interactions if they are not satisfied with them.

In summary, humans have inherent capabilities to monitor and correct the quality of their interactions-of what happens between them. The science of human communication offers an organic theoretical and methodological basis from which to observe quality in action. When the context is health care, quality control is then, a naturally occurring event. It's happening right under our scientific noses.

Health Care as Health Communication

Another common ground between the IOM Committee on Quality and NCI communication scientists is our shared view of health care as process. The IOM committee on quality defines health care as a function of its interdependence and interactions. It conceptualizes health care, not as a static institution, but as: "a set of connected or interdependent parts or agents—including caregivers and patients-bound by a common purpose and acting on their knowledge". This acknowledgment does not necessarily make it easier to reshape into a higher quality system. Health care is complex, the IOM committee continues, because of the great number of interconnections within and among small care systems. And, they argue, health care systems are adaptive because unlike mechanical systems, they are composed of individuals-patients and clinicians who have the capacity to learn and change as a result of experience. Their actions in delivering health care are not always predictable, and tend to change both their local and larger environments.(P.63-64"). In other words, health care systems are complex because human interactions--those inherently creative and unpredictable processes that occur each day, every day--are what drives and shapes them.

This dynamic view of health care is akin to the view of health communication researchers who claim that "health—like politics—is not an institution, but a set of collective behaviors that are formed and influenced through communication processes." Finnegan and Viswanath (in Kreps and Thornton, Health Com Theory and Practice, p14). Communication systems, like transportation systems, play a fundamental organizing function. A transportation system is a network of interconnected roads and highways, river ways and other links that determine and reflect the quality of travel, how we use these modes of travel and how efficiently and effectively we travel. Likewise, the kind of communication systems we design can determine the quality of health information and other health care services.

From a systems view where each person's action is another person's feedback, humans are adapting to each other constantly; during each communication exchange, with each assignment of meaning; each responsive act. In the health care context adaptation is happening when a doctor searches for a patient's reaction upon telling her that she has breast cancer. It happens when a patient tries to read a doctor's intention upon being told she needs another cat scan. It happens when a health care organization places patient educational material on their website, based upon focus group feedback. And, on and on in our daily interactions, emails, phone calls, visits between and among health professionals, patients, families, friends, and yes, even researchers. Even though we may take it for granted much of the time, we humans are rather busy complex systems, adapting to each other all the time in sometimes predictable but sometimes surprising and creative ways.

In summary, the health care system is the sum of the human interactions within it. The quality of their interactions serve as measures of its quality. It is daunting to imagine trying to redesign an entire health care system to achieve better quality. It is much more manageable

however to design patterns of human interactions toward that end.

Health Communication and Designing for Quality

Plsek (Crossing the Chasm appendex B) has argued that efforts to reduce the health care system to its components have failed at improving the system. From a systems view, whole systems can be designed in a way to harness the ongoing change through a simple set of rules, then observe how it changes rather than isolating its separate components or holding its dynamic characteristics constant. The IOM Committee on Quality concurs and has set forth the following a few set of design rules and observing the emergent qualities.

The committee offers six challenges to building quality systems of care:

1. Redesign care processes to serve more effectively the needs of the chronically ill for coordinated, seamless care across settings and clinicians and over time;
2. Make effective use of information technologies to automate clinical information and make it accessible to patients and all members of the care team.
3. Manage the growing knowledge base
4. Coordinate care across patient conditions, services and settings over time;
5. Continually advance the effectiveness of teams
6. Incorporate care process and outcome measures into their daily work. (p12)

We approach these challenges from a systemic model of human communication in which we see an isomorphism between improving the quality of health interactions and improving the quality of health care. This model offers a research method for designing human interactions that make up the health care process and observing changes in quality over the course of the interactions. In other words, the unit of observation is the interaction between health care participants. The research method this invites is the design of human interactions that reflect the characteristics of complex, adaptive systems and allow their inherent capacity for self improvement.

This interaction, from a systems view, is an organic approach to research. since it already has within it two critical components of quality improvement: the capability for creative change and a built in feedback loop for observing and adapting to that change. We believe this is an effective alternative way to conduct outcomes research and test interventions.

The Role of E-health

E-health, is the use of information and communication technologies within the context of health care. The essential ingredient of these technologies is their interactivity; they extend the human ability to create and manage their interactions in highly structured ways and are not bound by the constraints of time and place. The potential for e-health to radically change the way health interactions are conducted has yet to be tapped, much less, reached (Neuhauser & Kreps, 2003a, 2003b). We will illustrate this point in two research examples, below. But first, we will describe how a systemic health communication research approach, enhanced with e-health tools, can operationalize the IOM's design for quality challenge.

IOM Recommendations to Design to:	Health Communication Research Design To:
Make Patient Centered, coordinated and seamless	Support ongoing interactions, including frequent feedback opportunities, between care givers and their patients and family members
Make effective use of IT	Embed outcomes queries into ongoing interactions
Manage the knowledge base	Embed standards based or best of breed interventions into ongoing interactions and adapt interventions according to feedback
Coordinate across conditions, services, settings and time	Integrate human and e-health communication for continual personalization and localization
Continually improve teamwork	Create a web of interactions for all members of each team
Incorporate care process and outcome measures into daily work	Link all team interaction results to computerized patient record.

VA Project and Care Coordination

Citing organizational problems as key culprits in our efforts to manage chronic care. "The fact that more than 40% of people with chronic conditions have more than one such condition argues strongly for sophisticated mechanisms to coordinate care. Yet health care organizations, hospitals, and physician groups typically operate as separate 'silos', acting without the benefit of complete information about the patient's condition, medical history, services provided in other settings, or

medications provided by other clinicians." P2. executive summary.

In 2002 the National Cancer Institute and the Veterans Health Administration (VHA) initiated a joint research project for the purpose of developing a model of telehome care for cancer patients and their families. One of the primary goals of this effort is to test the viability of integrating outcomes research into the delivery of care process. The evolving model of cancer care reflects a systemic view of health communication. We will describe the contours of this research project here to lend pragmatic support to our earlier theoretical view of health communication as the dynamics involved in organizing health care systems.

The VA - an Exemplary Communication System.

The Veterans Health Administration has one of the world's most comprehensive and sophisticated computerized patient record systems. This record is the backbone for organizing interdisciplinary teams of caregivers around a single, real time view of a patient's health status. In the case of a cancer patient, the radiologist, oncologist, nurse, primary care provider, etc have access to each other's reports, test results, notes, prognosis, etc on line. This shared knowledge enables members of the team to engage in efficient and effective communication regarding the patient's status. By extending the computerized patient record to the Web, patients and their families and informal caregivers become part of the communication system that is made up of all the stakeholders in given patient's well being.

Home Care at the VA

It is within this elaborate e-health communication system that the VA has engaged in a bold effort to extend health care into the homes of thousands of veterans with chronic conditions. Beginning in April 2000 the Veterans Health Administration began testing a model of home based coordinated chronic care. Designed as an "aging in place" model of care by the Sunshine Network of the VHA (VISN 8 Veterans Integrated Service Network), the aim of this program is to " improve health status, increase program efficiency, and decrease resource utilization. (Meyer, et al, 2002, p87). After the first two years of operation evaluation results have shown:

- 40% reduction in emergency room visits
- 63% reduction in VHA nursing home admissions
- 88% reduction in nursing home bed days of care

The VHA, like all healthcare systems, is trying to manage the costs of chronic care. They face an increasingly older population and tightening budgets. In a break from traditional hospital-based VHA care, the Community Care Coordination Service (CCCS) in VISN 8 designed a working model of care that places communication and e-health at the heart of their community-based system of care. Over a million and a half veterans live in the VISN 8 service area, 45% of whom are 65 or older. 4% of these veterans were found to be consuming over 40% of the network's resources (Veterans Integrated Service Network (VISN8). Strategic plan. Department of Veterans Affairs, Bay Pines, FL:2001). This group was identified as "high risk, high use, high cost" (Meyer, p88) and the new coordinated care model was deployed to improve quality while managing costs.

Coordinated Home Care

The CCCS strategic model includes a business and clinical model. It links care coordinators and communication technologies to the seven hospitals, 10 multispeciality outpatient clinics, and 28 community based primary care clinics in the Florida and Puerto Rico VISN. In the coordinated care model at the VHA, each high cost, high risk, high use veteran is "assigned a care coordinator for the entire continuum of care. Care coordinators monitor patient problems and help resolve them whenever and wherever they arise" (Meyer, p.88). "The role of the care coordinator is a key factor in ensuring appropriate, timely patient data—which constitutes the most vital part of clinical decision-making-is communicated to the healthcare provider". P88. Care coordinators have been trained as social workers, nurse practitioners, and/or register nurses). Each is empowered to assess and make decisions across departments to enhance access to care and to eliminate bureaucratic barriers that sometimes prevent timely symptom management. The communication technologies are used to maintain frequent and timely communication between the care coordinator and the patient at home.

Feedback: The Essence of Care Coordination

Ongoing communication between patient and care coordination and between care coordinator and providers of care from across the VHA is the central dynamic of this innovative model. The infrastructure is in place to support communication involving three continually repeated activities: assessment, matching and monitoring.

- First, care coordinator and patient talk about the patient's clinical needs, functional status and the social and environmental context in which care occurs.

- Second, the care coordinator, in communication with various care providers, matches the services to the needs of the patient.
- Third, an ongoing feedback loop is installed in each patient's home to monitor patient's health status, quality of life, patient satisfaction and need for new or modified services. Various information and communication technologies are deployed, depending upon the fit with each patient's situation*

This model has proven to improve patient/provider relationships and improve patient satisfaction. Self management is another key component of this model. Technologies were chosen that supported patient compliance and provided educational opportunities to enhance self-management.

In a preliminary study, the CCCS program was compared with usual VHA care, which does not involve coordinated care or communication technologies. Results for the intervened group from the change in the first year to second year data analysis showed a reduction in ER visits by 40%, hospital admissions by 63%, and hospital BDOC by 60%. Nursing home admissions declined by 64% and nursing home DCOC were reduced by 88%. In the comparison group, nursing home admissions increased by 106%. Patients enrolled in the CCCS program were 77.7% less likely to be admitted to a nursing home care unit than those not enrolled in the program. Quality of life and functional liability as measured by the SF 36V indicated significant improvements in the physical, pain, social functional, emotional and mental composite scores. On performance dimensions, such as compliance with medication (93%) and appropriate, timely communication between primary care provider and the care coordinator (85%), scores are also impressive.

Overall, when comparing the intervened group findings to the comparison group, it was found that the intervened group showed considerably greater improvements on all measures. This communication system is proving to be effective in designing a proactive healthcare model that "facilitates patient-oriented and cost-effective delivery of services." VHA is so impressed it is planning to roll out to the care coordination system nationwide.

Coordinated Cancer Care

The National Cancer Institute has joined with the VHA in further elaborating on this coordinated care model to develop a model of home-based coordinated cancer care. Together, these two agencies will help meet two of the VHA's high priority goals as they design quality home-based systems of care that meet their growing need to deinstitutionalized health care:

1. A strategy for developing home-tele-health that is explicit and evidence based.
2. A set of uniform standards for home-tele-health in the VA

This collaborative research project will also help meet two of the eNCI's high priority goals as we focus on the chronic nature of cancer and those who must manage this condition over time:

1. Develop quality standards for information and communication technologies that can be used to support providers, patients and caregivers
2. Develop models of coordinated and secure systems of cancer care that are patient-centered and patient-friendly.

The proposed VISN 8 Home & Community Care Model is central to veterans and caregivers. The entry point of the veteran into home care can be from anywhere along the continuum of care, for example, acute care, nursing home, or primary care settings. This continuum of care framework is supported and strengthened by focusing on clinical outcomes and quality, use of state-of-the-art technology, and on-going education and research with special emphasis on customer satisfaction and good communications. Services available will be standardized across the network through new program developments including: telemedicine clinics, network Telephone Care Program, in-home respite services, consolidated contracting for services, and new partnerships.

The care coordinator will have both clinical and administrative background and experience and will be responsible for following patients to assure timely and appropriate movement through all levels of the care continuum. The care coordinator will be knowledgeable about all services accessible to patients and caregivers in the home including those available through newly emerging technology. The coordinator, directly responsible to the VISN Home Care leadership, will be located at the local pilot site and will serve as a link between the hospitals, discharge planning team, primary care provider, home care staff and other professionals involved in the patients' care. The care coordinator, assisted by the Network Telephone Care Program, will assure the patient is provided support 24 hours a day, seven days a week.

Long-range program goals include:

1. Expanding the use of patients' homes as alternate clinic sites through the use of technology; this will allow full development of the primary care concept with the team involved in all facets of patients' care outside an inpatient stay.
2. Developing a process for managing all VA and VA sponsored visits to patients' residences
3. Exploring and developing new resources to enable patients to remain in their homes

4. Exploring and developing the care coordinator role to impact on high risk, high cost patients' care through the continuum.]

Research as Dialogue.

One of the defining characteristics of the care coordination model is the ongoing dialogue between the care coordinator and patients. Every qualifying veteran in VISN 8 is assigned a care coordinator for the duration of his chronic condition. Although the care coordinator is an infrequent visitor in the veteran's home, they communicate on a daily basis via a variety of technologies, including telephone, picture phone and/or "dialogue boxes". The dialogue box is what makes it viable to integrate outcomes research into this ongoing flow of communication.

The dialogue box is a small in-home messaging device. It is a web-based, store-and-forward application that connects to the care coordinator through the Internet from the patient's home via a toll-free number, requiring no technology know-how. The dialogues are highly structured questions and answers regarding symptom management, self-management and disease knowledge for a variety of chronic conditions. This dialogue is highly structured (standards driven) and partly automated, using a communication technology placed in the patient's home, along with personal communication when needed. This system accomplishes a number of things at once:

- It monitors compliance, health status and quality of life on a daily basis.
- It collects and stores baseline patient data against which daily adjustments can be made.
- Behavioral interventions, health promotion and patient education are incorporated into the dialogue when appropriate.
- Data collection occurs in the context of an ongoing relationship between the patient trusted care coordinator.
- Patients who normally would have to have extensive nursing home or hospital care can stay at home.

Each veteran is expected to engage in a brief dialogue each day. Care coordinators are able to access the answers over a secured website in near real time. Using this communication process care coordinators receive ongoing feedback concerning the health status and knowledge based resources available to each patient. Answers become data, that, collected in a database (what kind?) over time reveals a highly accurate profile of the patient's progress. If a particular answer is outside the latitude of acceptable health condition, according to the standard of care an alert automatically becomes part of the patient's response. The care coordinator, upon receiving the alert, can inquire further and/or contact a health care provider immediately.

The dialogue box holds, in microcosm, the essence of systemic communication in which ongoing reciprocated feedback facilitates adjustments and adaptations in an ongoing basis. In it communication and outcomes research become a fully integrated process in which interventions can be tested, altered and tried again as part of the daily exchange between patient and care coordinator.

E-Health as Dialogue

E-health technologies provide a unique opportunity for establishing meaningful interactions between health care providers and consumers, as well as with health researchers, who seek to learn more about the role of communication in providing high quality care. The electronic interactions among the participants in the modern health care system allow development of evolving cooperative relationships, sharing of relevant information, identification of emergent health problems and issues, and the ability to intervene early to ameliorate these problems before they spiral out of control. This opportunity for dialogue provides consumers with greater access to their different health care providers, allows them to ask questions to guide health maintenance activities, and empowers them to take care of themselves. Dialogues provide health care providers with the opportunity to educate consumers, learn about their responses to treatment, track their clients' changing conditions, and answer any questions that arise, both from consumers and from local caregivers. This dialogic communication has the potential to help increase reach, influence, and coordination for all members of the health care system.

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