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Healthcare System Approaches for Cancer Patient Communication

JOHN M. QUILLIN,

Department of Human & Molecular Genetics, Virginia Commonwealth University (VCU), Richmond, Virginia, USA

KELLY TRACY,

Virginia Commonwealth University (VCU), Richmond, Virginia, USA

JESSICA S. ANCKER,

Columbia University, New York, New York, USA

KAREN M. MUSTIAN,

University of Rochester, Rochester, New York, USA

LEE ELLINGTON,

University of Utah, Salt Lake City, Utah, USA

VISH VISWANATH, and

Harvard University, Boston, Massachusetts, USA

SUZANNE M. MILLER

Fox Chase Cancer Center, Philadelphia, Pennsylvania, USA

Abstract

Cancer patient communication is always embedded in a complex background of inter-related parts, i.e., a system. Cancer patients are specifically exposed to a *healthcare* system. Considering this context, this article summarizes the insight from a roundtable discussion involving behavioral medicine and oncology experts convened at the 2008 Annual Meeting of the Society of Behavioral Medicine as part of an annual pre-conference course entitled “Interpersonal Communication and Cancer Control: Emerging Themes”. In this paper we summarize the communication-relevant components of healthcare systems, focusing on the macro level. Next, we review existing theoretical frameworks for systems-based communication, the unique aspects of “systems thinking,” and the emerging systems tools that can be integrated in cancer communication. Finally, we propose a research agenda for successful system approaches for patient-centered cancer communication.

Introduction

Individuals who are diagnosed with cancer become patients in a broad and very complex “healthcare system” that is comprised of many inter-related, but also independent, systems (e.g., insurance, primary care, surgical oncology, medical oncology, radiation oncology, psychiatry, rehabilitation) creating an intricate multi-system network. In order to receive high quality and effective care after diagnosis, cancer patients must navigate this healthcare system and communicate with a wide variety of individuals to make informed decisions about their treatment choices, side effect management, daily life activities, plans for the future, and

continued survivorship or death. Systems theories (discussed in more detail below) account for these multi-leveled intricate networks, recognizing that successful cancer communication interventions that focus on only one variable (e.g., patient values) or limited to a single ecological level (e.g., individual versus interpersonal) are less likely to be successful than a holistic approach. Systems theories at the macro level provide frameworks by which research in the field of cancer communication can account for and intentionally intervene upon the broader healthcare system. In this article, we begin by outlining major components and categories of healthcare systems important for communication with patients who experience a cancer diagnosis. We have centered our discussion on the institution of healthcare as the primary system of interest. There are many other systems in which the consumer operates (e.g., familial, cultural) and which influence the individual's encounter with the healthcare system. Further, there are macro-level communication channels that are not particularly specific to healthcare systems (e.g., television, internet, billboards) that could also effect and/or be the conduit of cancer communication. Although important, a thorough review of these is outside the scope of this paper. Next, we explore existing theoretical frameworks for systems-based interventions and the unique aspects of systems thinking. We then explore existing and emerging tools for systems-based cancer communication. Finally, building on these examples and incorporating new insights from systems-based disciplines, we suggest strategies for increasing success in this promising line of cancer communication research. We aim to highlight the key characteristics of systems research, important existing lines of research, and promising future directions.

The Healthcare “System” for Tertiary and Quaternary Cancer Care

In this article we focus on communication with patients who have already experienced a cancer diagnosis, i.e., tertiary and quaternary cancer prevention communication. The aims of tertiary prevention are to reduce morbidity and mortality among patients who have already been diagnosed with cancer. Quaternary prevention, similar to palliative care, aims to alleviate suffering and optimize end-of-life care. Compared to primary prevention (reducing the chance cancer will occur) and secondary prevention (screening for early-stage disease), individuals who might benefit from tertiary and quaternary prevention strategies share a context – an intimate interaction with the healthcare system about their cancer care. As with other aspects of cancer care, cancer communication strives for high quality, such as the six quality aims proposed by the Institute of Medicine (effective, safe, timely, efficient, equitable, and patient-centered) (Institute of Medicine (IOM), 2001). Communication strategies relevant for this context and these goals, then, are a focus of this review.

Generically, a system is “a group of interacting, interrelated, or interdependent elements forming a complex whole” (Houghton Mifflin Company, 2006). In healthcare, systems involve actors and tools at all levels – the macro level (e.g., third party payers, electronic medical records), interpersonal dynamics (power structure, decision-making role preference), and individual personality differences and unique circumstances. They encompass all of the multi-leveled people, places, tools, organizational structures, and circumstances associated with the care of a patient, as well as the connections between them.

Figure 1 presents these various components of the healthcare system. Ultimately, these system components make up the context for communication between patients and health care providers (or their technological mediators such as websites, brochures, or kiosks). Out of this complex context emerges some kind of connection (or not) involving a cancer patient. If successful communication occurs, a therapeutic alliance is established leading to some outcome of importance. For tertiary and quaternary cancer care, these outcomes could include informed decision making about clinical trial enrollment, treatment adherence, or a “good” death with minimal suffering.

For a long time, the intra- and inter-personal dynamics of cancer patient communication have been research foci. They should continue to be. However, systems-based approaches must integrate these aspects into the bigger picture of healthcare – often depicted at the macro level, from an ecological perspective. For systems to exist and function, communication must be established and maintained among actors within and between (i.e., at the intersection) each of these ecological levels (Viswanath, 2006). There remain important challenges, some broadly applicable and some unique to healthcare in the United States, particularly for macro-level aspects of the healthcare system that could impede effective cancer communication.

The greatly decentralized, fragmented nature of healthcare presents significant challenges to health communication for cancer patients. Cancer patients receive care from multiple specialists (radiation oncologists, medical oncologists, genetic counselors, social workers, surgical oncologists, etc.). The coordination of care among the specialists is often fragmented and seldom team-oriented, leading to communication gaps among them as well as patients. Moreover, most patients are not seen in comprehensive cancer centers with multidisciplinary teams. So, communication between these specialists and the patient's primary care physician is a significant concern with potential for breakdown (Aiello Bowles et al., 2008). This breakdown in communication can happen at multiple points and for many reasons. Patients might not know the names of all of their specialists or understand their healthcare roles. Medical records, radiology films, and other important patient data may not be sufficiently or efficiently transferred from one specialist to the other. At a more distant level, insufficient communication with public health databases, such as cancer registries, ultimately affects communication with patients when the public health knowledge generated from those data fails to be translated to individual patient care initiatives.

Financial systems also potentially impact cancer care, likely mediated through communication with patients. For example, insurance status may predict which cancer specialists interact with patients, what treatments patients receive, and how adherent patients are with follow-up (Bradley, Neumark, Shickle, & Farrell, 2008; Bradley, Given, Dahman, & Fitzgerald, 2008). It is unexplored, but plausible, that patient-provider communication mediates, or partially mediates, this process. Related, reimbursement systems that reward according to procedures rather than patient outcomes may be less likely to support cancer control outcomes and quality care (Aiello Bowles et al., 2008). Such frameworks may in fact contribute to higher costs [e.g., unnecessary chemotherapy at the end-of-life (Payne, Coyne, & Smith, 2002)]. Insurance deductibles, co-pays, levels of reimbursement, or lack of any insurance constitute the financial macro system, which likely influences both patient and provider decision making during cancer treatment discussions.

In addition to information from other providers and third-party payers, various policies and guidelines can broadly and differentially affect cancer communication. Cancer treatment guidance comes from many sources with varying authority and enforcement. Related to the above discussion of financial systems, insurance company reimbursement criteria may strongly influence the range of cancer treatment options discussed with patients. Guidelines from various professional organizations (e.g., National Comprehensive Cancer Network) may offer a multidisciplinary perspective, but often patient-provider discussions remain “provider-centric” (Aiello Bowles et al., 2008), reflecting the fragmentation of specialty cancer care and, again, the financial reward system.

The physical environment in which cancer communication takes place is also important. Did a patient have to drive two hours to find a radiation oncology facility? If so, that could influence the discussion of treatment choices. A recent large epidemiologic study, for example, found that breast cancer patients seen in urban centers were more likely to receive adjuvant radiation therapy (Hershman et al., 2008). Other physical variables are likely to impact cancer

communication, but may have been less studied. Did the discussion take place in an exam room or a more comfortable consultation room? Did the patient have to fight traffic or walk a long distance from the parking garage, delaying arrival and shortening the amount of time for discussion? Did the clinic or hospital hours mean a patient had to take time from an hourly-paid job, adding stress to the communication encounter? Was the call center staff that scheduled the patient for an appointment personable and welcoming, setting a tone for open patient discussion at her visit? Each of these organizational variables – broadly applicable across a variety of patients and providers – likely impacts cancer control outcomes, mediated by patient-provider communication.

Theoretical Frameworks and Unique Aspects of “Systems” Thinking

As with most interventions, integration of systems-based tools for effective cancer control is more likely to be effective if it is guided by theory (Bowen et al., 2006; National Cancer Institute, 2005). To date several theoretical, conceptual, and evaluative frameworks have been employed to affect cancer communication at systems levels [e.g., (Glasgow, 2007; Squiers & Treiman, 2006)]. Major frameworks include the Diffusion of Innovation Theory (Rogers, 2003), the RE-AIM (Reach, Efficacy, Adoption, Implementation, Maintenance) framework (Glasgow, Vogt, & Boles, 1999), the PRECEDE-PROCEED (Predisposing, Reinforcing, Enabling Constructs in Educational/Environmental Diagnosis and Evaluation – Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development) model (Green & Kreuter, 1992), the Social Ecologic Framework (Dahlberg & Krug, 2002), and the Health Behavior Framework (Jo, Maxwell, Wong, & Bastani, 2008). A brief characterization of each of these frameworks is presented in Table 1.

These models are particularly amenable to systems thinking because they focus on process (consider simply the action-oriented acronyms “RE-AIM” and “PRECEDE-PROCEED”), and they include the organizational contexts, emphasizing the ability of interventions to be robust for dissemination research. Unfortunately, these frameworks have not been consistently and sufficiently applied to cancer control research generally (Glasgow, Marcus, Bull, & Wilson, 2004; Squiers & Treiman, 2006), much less applied to tertiary and quaternary cancer prevention communication in which the healthcare system is key. Moving forward, not only will cancer communication interventions need to employ these systems-based models, but their implementation and evaluation will need to embrace the unique aspects of systems thinking.

Systems, by nature, are “interacting, interrelated, and interdependent.” Intervening at any one level of the system, or on any one characteristic within a level, will very likely alter the rest of the system – predictably or not. This is the essence of complexity theory, and it has important implications for systems-based communication study designs. For example, from such a perspective, investigating the statistically independent effects of variables may not make sense or lead to practical solutions for effective cancer communication.

Other unique aspects of systems-based interventions have to do with what intervention implementation strategies are chosen and how new information is generated (Bammer, 2005). Because of the importance of context, while individual and interpersonal variables cannot be ignored in systems research, there is necessarily a stronger focus on the organizational culture and priorities. Knowledge communicated within the system is nuanced by all of these contingencies (see Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004). Use of interdisciplinary teams, participatory action research methods, and built-in mechanisms for evaluation and feedback are perhaps more important, then, in systems-based research. Along these lines, systems-based research outcomes may be more informed by process evaluations, rather than traditional summative, or outcome, evaluations. This is because the success of systems-based interventions is so context-dependent. Further, because of the

context-dependency of systems approaches, there may be a need for greater focus on effectiveness studies with an eye toward dissemination, rather than tightly controlled efficacy studies, as Glasgow and others have discussed (Glasgow et al., 2004; Glasgow, 2007). While traditional randomized controlled trials focus on individual outcome predictors and internal efficacy, dissemination research focuses on external validity, i.e., robustness across contexts.

Current and Emerging Systems-Based Tools to Address these Challenges

What tools can be integrated into systems theories to address, especially, macro-level, or organizational, system challenges? Several tools are being investigated, including electronic media and informatics, other communication media, and patient navigators.

This decade has seen an explosion of electronic information systems for hospitals, individual clinicians, and public health systems. These systems have not yet reached their potential, but they could facilitate rapid, accurate, and scaleable data collection, data storage, data retrieval, and data sharing (Kukafka et al., 2007; The Markle Foundation, 2003). Such systems clearly have enormous implications for systems communication. For example, a state-of-the-art electronic system could facilitate intra-system communication of patient data, which provides a substrate for meaningful interpersonal communication among clinicians as well as between clinicians and patients. Improved medical data sharing could be a benefit. For example, continuity of care would likely improve if the primary care physician had seamless access to his or her patient's hospital data. Another system-wide benefit could be improved tracking of public health problems through the collection of individual clinical data, instead of, as is often the case currently, waiting for physicians to complete paper reports and send them to public health departments (a process known to be slow, inconsistent, and incomplete) (The Markle Foundation, 2003). However, as these electronic systems are implemented, we could also see adverse effects. Imagine a patient whose mistaken diagnosis follows her for years, or data collection systems that impinge on personal privacy (Koontz & Power, 2007). Systems-wide research into the process and effect of accessible electronic medical information on communication is essential. (For a more comprehensive review, see the May 2007 Supplement to *American Journal of Preventive Medicine*, "Critical Issues in eHealth Research".)

Electronic tools do not need to be limited to desktop computers. Telephone resources have been widely used for primary and secondary cancer (e.g., Cancer Information Service). Phone technology is currently being explored in tertiary and quaternary cancer control interventions, too. For example, phone systems linked to electronic medical records or direct care providers have been investigated as a way to report chemotherapy side effects (Sikorskii et al., 2007; Weaver et al., 2007) or screen for depression in cancer patients undergoing treatment (Downe-Wamboldt et al., 2007). Handheld computers have been studied for similar purposes (Kearney et al., 2006). Information technology tools such as these may help to reach patients who otherwise could not be practically contacted and, especially with automated systems linked to electronic medical records, could reduce disparities in cancer care.

As a lower technology alternative, patient navigators have recently been proposed to link the disparate parts of the healthcare system. Patient navigators are personnel trained to assist individual cancer patients as experts in community and hospital resources relevant for patient care (Hede, 2006). Although it is a relatively new concept, patient navigators are proving to be an effective systems-based strategy for improved cancer care. Related projects have shown they may reduce cancer care disparities (Hede, 2006; Schwaderer & Itano, 2007), improve follow-up of abnormal mammograms (Battaglia, Roloff, Posner, & Freund, 2007), reduce related anxiety (Ferrante, Chen, & Kim, 2008), and appropriately triage cancer patients for genetics assessment (Rahm, Sukhanova, Ellis, & Mouchawar, 2007).

Future Directions

Considering research to date and the presented conceptualization of the healthcare system, we envision the following opportunities for growth. There is a need for comprehensive analysis and evaluation that is not limited to individual determinants of cancer control outcomes, a focus on process evaluation, greater use of existing multi-level frameworks that emphasize organizational contexts, broader interdisciplinary collaborations, and attention to equitable implementation and impact of systems-based communication interventions.

These approaches will present new challenges and require new ways of thinking. For example, when utilizing multi-level approaches (e.g., Social Ecologic Framework), there is a need for evaluation that addresses complexity at, and between, various units/levels [e.g., multilevel modeling (Epstein & Street, 2007)]. Cancer research broadly has entered the “-omics” era. Tertiary and quaternary cancer control research is embracing new disciplines such as genomics, proteomics, metabolomics, and transcriptomics. Perhaps cancer control researchers similarly need to embrace a “communicomics” perspective, i.e., one that embraces the holistic impact of system-wide communication, rather than searching for the independent effects of individual system components.

Secondly, the ends (i.e., outcomes) of this type of research may well be the means (i.e., processes) of communication. Thus, encouragement of process- and formative-focused research questions is needed, rather than traditional summative outcomes research that might have limited potential for dissemination. These research questions stray from the traditional “What works?” to questions like “For whom does it work?” and “Under what circumstances?” What will likely emerge from this type of research are broad core effective principles for cancer communication that are suitable for dissemination. A systematic science of cancer communication research dissemination will likely require continued emphases on information technology tools, humanistic tools like patient navigators, and broad-based interdisciplinary approaches. Collaborations involving psychology, decision-making and behavioral science, and oncology will need to extend to include such disciplines as systems theory, classical communication theory, informatics, and organizational behavior.

Finally, it is critical that, as we move forward, systems-based cancer communication works to reduce health disparities, rather than exacerbates them. Health disparities unfortunately pervade many aspects of cancer research (Cooper & Roter, 2003), and communication research is no exception. In principle, consistently applied, broad-based systemic approaches should ensure that all patients are treated equally. Yet many of the cancer communications tools that could be used by systems, such as the internet, are variably utilized by persons of different racial and socioeconomic backgrounds (Viswanath, 2005, 2006). As systems-based communication research advances, social inequalities in the generation, dissemination, and use of health-relevant information must be carefully examined.

For better or for worse, cancer patients are embedded in increasingly complex healthcare systems that do not appear to be simplifying. By building on current systems frameworks and adjusting the research foci, future cancer communication research can optimize chances for successful tertiary and quaternary cancer control.

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Figure 1.
A model for system communication in the health care system.

Table 1

Brief description of model=frameworks.

Model/Framework	Brief description
Diffusion of Innovation (Rogers, 2003)	Investigates the process in which new communication tools are adopted within an organization. Important variables include how well information is communicated, the relationship between intervention developers and users, and environmental support.
RE-AIM (Glasgow et al., 1999)	Assesses the likelihood an intervention will be successfully implemented within a system based on its potential for efficient, broad adoption of the intervention, implemented by a wide variety of organizations.
PRECEDE-PROCEED (Green & Kreuter, 1992)	Interventions are designed based on initial assessments of macro-level (environmental), social, and individual factors likely to contribute to success.
Social Ecologic Model (Dahlberg & Krug, 2002)	Interventions are designed to improve communication considering variables at multiple levels – individual, interpersonal, organizational, and environmental.
Health Behavior Framework (Jo et al., 2008)	Combines constructs from the PRECEDE-PROCEED model with cognitive decision-making and intention-based models such as the Health Belief Model and the Theory of Planned Behavior.