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Cancer and Patient-Physician Communication

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Introduction

This paper reviews some of the new evidence-based approaches and interventions in cancer communication aimed at improving cancer care. This paper will address challenges specific to cancer communication, between patients and health-care professionals. Throughout, we will discuss the importance of establishing structures to optimize patient communication, highlighting the example of pregnancy support programs as a potential model. We conclude by addressing critical areas for future research, including peer-to-peer patient communication and the challenges brought on by new technologies.

Importance of research in patient communication

In the past few decades, patients have become increasingly involved in directing their own medical care. Patients diagnosed with cancer are not only coping with the emotional trauma of a cancer diagnosis; they are also expected to digest complicated and often threatening information about treatment procedures. Patients seek out information and approach their health care providers as informed consumers rather than as passive recipients of advice and treatment, with regard to health decision making and behavior. Two reviews have underscored the importance of patient-physician communication (Stewart, 1995; Ong, de Haes, Hoos, & Lammes, 1995). Stewart (1995) identified a positive association between improved patient health outcomes (e.g., patients' emotional status, physical health, blood pressure and blood glucose level) and good patient-physician communication behaviors (e.g., physicians inquiring about their patients' emotions). Ong and colleagues (1995) also reviewed evidence for such associations, focusing on a broader range of patient outcomes (i.e., satisfaction, compliance, recall and understanding of information, physical and mental health). In addition, they proposed a framework to explain how the quality of patient-physician communication informs patient outcomes. This framework includes such factors as: patient/physician background, (e.g., cultural background of patients and/or physicians), the relationship between doctor and patient (e.g., physicians' expression of affective behavior, such as behaving in a more, or less, dominant, controlling style of communication); and the functions and content of patient-physician communication (i.e., types of communicative behaviors like instrumental (or "cure-oriented") and/or affective (or "care oriented")). According to their framework, background variables inform the actual content of communication and communicative behaviors; the communication and resulting behaviors, in turn, determine short-term and long-term patient outcomes. More recently, a review by Makoul and Curry (2007) summarized prior findings by demonstrating that effective patient-physician communication is related to improved adherence to medical regimens, better decision making, fewer claims of malpractice, and increased satisfaction with the patient physician relationship.

Current theoretical approaches and interventions

Efforts have been made by several researchers to develop theoretical frameworks, such as the example above (Ong et al., 1995), to better characterize patient-physician communication and to develop interventions to improve such interactions. In addition, there are some interventions that target communication behavior directly by focusing on patient education and providing information on disease and treatment with the goal of focusing the physician communication on the critical individual and clinical factors. There are others that address it more indirectly, targeting decision making when taking into account the impact on physician communication. What follows are some recent examples of these two types of interventions. Given the restrictions of space for this article, we are limiting examples to three representative interventions.

a) Patient-directed interventions

The PACE (Presenting, Asking, Checking, Expressing) system is a patient education system designed to improve communication with physicians, with the aim of enhancing patient adherence (Cegala, McClure, Marinelli, & Post, 2000; Cegala, Post, & McClure, 2001). The development of PACE was prompted by the observation that patients typically do not engage in much information seeking during medical interviews, even though they usually state that they want as much information as possible (e.g., Beisecker & Beisecker, 1990; Street Jr., 1991). Many patients tend to seek information through indirect methods, rather than direct methods (e.g., asking the physician questions; Cegala, 1997; Quill, 1989). PACE was therefore designed as a patient communication training tool, emphasizing the acquisition of proficiency in four specific categories: 1) presenting detailed information about how patients feel

emotionally; 2) asking questions if desired information has not been provided; 3) checking their understanding of information that is given; and 4) expressing any concerns about the recommended treatment.

In a subsequent study testing this approach, Cegala, Street, and Clinch (2007) found supporting evidence, by using the categories of the PACE system as the basis for coding patient-physician interactions. They found that patients' participatory communication style in a medical interview improved and influenced how physicians communicated with them. They found that physicians provided more information when communicating with high-participation patients compared to interacting with low-participation patients. These results fit with the more general expectations of daily conversation, in which participants align their actions to accomplish individual and mutual goals of communication, while also trying to maintain order and politeness (P. Brown & Levinson, 1978; S. C. Levinson, 1983; Tracy, 1991). For example, in general conversation there is the expectation that when one person asks another a question, an answer will follow (although there can be exceptions based on communicative contexts; for details, see Robinson, Shepherd and Heywood, 1998). Cegala and colleagues found that the same principle held during medical interviews. However their research also suggested that patient communication behavior, measured by their questions, assertive utterances, information provision, and expression of concern, influences physicians' discourse beyond simply answering patient questions.

To improve patient communication behavior, large scale efforts are required. Milewa and colleagues (Milewa, Calnan, Almond & Hunter, 2000) found evidence for the successful application of patient education materials on patient recall of health information and communication behavior.

b) Provider-directed interventions

Principles uncovered in basic communication research discussed above also have been applied to interventions targeting providers. Back and colleagues (2007) designed a curriculum for oncology fellows to improve commonly-faced communication challenges (e.g., giving bad news to a patient). This physician-focused workshop, Oncotalk, incorporated features of other physician training programs (Fallowfield, Jenkins, Farewell & Solis-Trapala, 2003; Maguire, 1999; Parle, Maguire & Heaven, 1997) and used learning activities such as skills practice sessions, reflective discussions, and "cognitive road maps" for common communication tasks, including the necessity of conveying bad news and discussing the option of palliative care. This material was based on empirical studies of patient preferences, and was subsequently tested. After attending a four day Oncotalk workshop, physicians gained skills in the areas of a developing relationships with patients, dealing with uncertainty, giving bad news, discussing transition to palliative care, and discussing do-not-resuscitate orders. The program appeared to have an immediate impact on physician communication behavior: one participant, upon returning to her clinic after the Oncotalk training program was told by a patient that "No one has ever talked to me like this (Back et al., 2007)."

c) Multimedia interventions

In recent years, there has been a trend to develop education and communication aids for new media applications. An example is The Prostate Interactive Education System, or PIES (Diefenbach & Butz, 2004), a tool, designed to educate patients about their treatment options after a prostate cancer diagnosis. The tool is intended to facilitate treatment decisions, and focus patient-physician consultation on the necessary clinical factors (e.g., stage of disease) and individual patient factors (e.g., preferences regarding future quality of life). PIES presents as a virtual health center, organizing information in different "areas" (i.e., reception area, a library, physician offices, group meeting room). Development of the PIES program was guided

by self-regulation theory (Leventhal, Diefenbach, & Leventhal, 1992; Miller & Diefenbach, 1998), which argues that illness cognition (i.e., expectancies, values and goals, and illness beliefs) and affect (i.e., positive and negative feelings about disease and treatment) influence decision making and health behavior. Preliminary analyses of a randomized trial suggest that the program is successful in reducing patients' decisional conflict and reducing decisional regret over time (Diefenbach, Mohamed, & Hall, 2008).

Methodologies for implementing patient communication interventions

In recent years, patient information and satisfaction have begun to receive more attention. Indeed, the American Society for Clinical Oncology (ASCO) has published Patient Guides with recommendations for a variety of cancers. These guides are summaries based on ASCO Clinical Practice Guidelines that are written in an accessible format, and offer patient-oriented information, providing background information on the disease, an explanation and discussion of the recommendations, and a list of questions to aid patients in their discussions with their doctors. The National Cancer Institute and the American Cancer Society have developed similar pamphlets. However, as the best system of delivery has not yet been developed, efforts need to be made to establish structures that would optimize physician discussions with their patients.

Programs do currently exist that could be used as models for patient communication, to ensure that physicians be more proactive about providing patients with relevant information, before the patient asks for it. It could be helpful to look at one successful model of a predictable, manualized health experience such as childbirth, a process in which the provision of information and support is written into state and federal law, and encompasses a variety of health care providers.

Currently, women who are pregnant (and have access to, and are able to participate in, regular health care) are automatically directed to education programs about nutrition, pre- and post-natal care. Commonly offered classes for expectant parents include Lamaze techniques, breastfeeding, sibling preparation, and infant care. Social support through social workers and lactation specialists is often available. Nurses, who are primarily responsible for a patient's care, are available to answer any questions after the baby is born, concerning the mother's health or the infant's care. This type of education is generally covered by most insurance plans. For those who are eligible for Medicaid, childbirth education also may be covered, depending on the state. For example, in Washington State, the 1989 Maternity Care Access Act, known as the First Steps program, provides maternity care before and after pregnancy and health care for infants. This includes obstetrical care and case management, as well as supportive services such as community health nursing, nutrition, behavioral health visits, and childbirth education classes.

Although not all elements of this highly successful program might be transferable into the cancer context it nevertheless could serve as a blueprint for managing the information needs of cancer patients. The complexities of a cancer diagnosis and its treatment make an optimal patient-physician communication process even more important and call for the development of new educational models that go beyond the traditional patient education approach. The challenges for health communication presented by a cancer diagnosis requires the collaboration of a multidisciplinary team consisting of doctors, psychologists, social workers, and nurses all working together to enhance understanding, adaptation and ensure survival and optimal quality of life.

Critical areas for future research

Patient to Patient Communication

A phenomenon worth examining more closely because of its growing ubiquity is patient to patient communication and information sharing (e.g., Rini et al., 2007), as seen on websites such as “PatientsLikeMe.com,” which is an example of a consumer-driven initiative to inform fellow patients. PatientsLikeMe was founded in 2004 by three MIT engineers after a relative was diagnosed with Amyotrophic Lateral Sclerosis (ALS). The family was active in the patient’s care, and was looking for novel ideas to extend and improve the patient’s life. PatientsLikeMe was designed to allow patients to report on and track their symptoms, medication use, and the progression of their disorders, and share these results with other patients. The ultimate goal of the website is to collect and share this real world, outcome-based patient data with doctors, pharmaceutical and medical device companies, researchers, and non-profit organizations to improve treatment and quality of life. There is little research on the impact of patient-to-patient communication on medication adherence, care-seeking behavior and patient quality of life. As such communications are likely to increase through dedicated Internet sites and social networking possibilities; research is needed to formally evaluate such interactions.

New Technologies

New technologies have increased the amount of available medical information and have created challenges regarding how to convey this information. 23andMe is a direct to consumer (DTC) genetic testing service that was founded in 2006. The company provides information on the variations that can occur at various meaningful places in a person’s genetic sequence (and in their mitochondrial DNA). Single nucleotide polymorphisms (SNPs), form the basis for the genotyping technique used by 23andMe. In addition to this genetic analysis, 23andMe provides interpretative information in a “Gene Journal” consisting of an Odds Calculator for disease risk, informational graphics, glossaries, and answers to frequently asked questions. No information is available on the uptake of genetic testing services, patient satisfaction and the impact of the results of testing on health behaviors.

Because of both the complexity and the limitations of genetic information, the need for proper interpretation of the results is crucial. Indeed, the American College of Medical Genetics (ACMG) issued a statement outlining the minimum suggested requirement for DTC testing. Their guidelines state that a “knowledgeable professional” should be involved, to avoid pitfalls such as “lack of informed consent, inappropriate testing, misinterpretation of results, testing that is inaccurate or not clinically valid, lack of follow-up care, misinformation, and other adverse consequences” (ACMG, 2008). A critical evaluation of how patients process their genetic information is needed. In particular, it is important to understand how individuals might affectively and/or cognitively process information about a health threat which may not appear for decades, and for which effective treatments may not be currently available.

As Marteau and Lerman (2001) point out, personalized information about risk for disease is not new, and the question remains whether or not people will be any more or less likely to act upon information based on DNA. Depending on the disease and the genetic information, there is some evidence that motivation to change behavior may either increase or decrease, based on beliefs about the effects of behavior in combination with the propensity for the disease (and beliefs about the immutability of the risks conveyed by the genetic marker), and beliefs about effectiveness of treatment in the face of genetic predictors. For example, in one study a majority of women with a family history of breast cancer said they would not undergo prophylactic mastectomy if they were found to have a risky mutation (Eisinger, Geller, Burke, & Holtzman, 1999). Another more recent study (Rees, Gaff, Young, & Martin, 2007) found that women who

received genetic counseling for breast cancer reported confusion and uncertainty about how health behaviors and breast cancer risk interact. In that study, genetic counseling had little impact on health protective behaviors among these participants. However, when a potentially modifiable behavior such as smoking was examined (Carpenter, et al., 2007), participants testing positively for the presence of a genetic marker conferring a high likelihood of developing emphysema due to exposure to cigarette smoke sought information on treatment, used pharmacological aids for smoking cessation, and were more likely to report greater reductions in their smoking.

As these few studies demonstrate, little is conclusively known regarding how individuals will act in the face of genetic information. We are in need of communication models and theoretical frameworks that take into account the various information needs of individuals and the rapidly changing scientific environment. This is particularly important in light of the fact that the identification of (and diagnostic and predictive tests for) genes which cause Mendelian disorders (which constitute only a small proportion of diseases that exist in the population at large), and genes that contribute in less direct ways to the development of disorders, will undoubtedly lag behind the development of safe and effective treatments (Holzman & Marteau, 2000).

Other considerations

Other important considerations that might impact successful communication between provider and patient are cultural differences, mistrust of medical professionals, age-specific considerations, and socioeconomic and educational status (see, e.g., Thompson, Valdimarsdottir, Jandorf, & Redd, 2004; Bigby & Ashley, 2008). Among older adults, physiological and cognitive deficits, and patterns of information seeking that differed from those of younger adults, might present additional challenges to effective cancer communication (Sparks & Nussbaum, 2008).

Conclusion

While basic models of patient-provider communication have been developed, there is a need to explore and understand the impact of the rapidly evolving communication technologies on information processing, decision making and health behavior. In particular, research should explore how novel communication practices can be harnessed to enhance understanding of genetic, disease, and treatment information, with the goal to facilitate treatment decision making, enhance health behavior and improve quality of life. In addition, there is a need for new theoretical approaches, developed by multidisciplinary teams of researchers that integrate the various challenges touched upon in this paper.

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