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Communication and Decision Making in Cancer Care: Setting Research Priorities for Decision Support/Patients' Decision Aids

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Abstract

The following is a summary report from a special symposium, entitled “Translating Research into Practice: Setting a Research Agenda for Clinical Decision Tools in Cancer Prevention, Early Detection, and Treatment”, that was held on October 23, 2005 in San Francisco at the Annual Meeting of the Society for Medical Decision Making (SMDM). The symposium was designed to answer the question: “What are the top two research priorities in the field of patients' cancer-related decision aids?” After introductory remarks by Dr. Barry, each of four panelists—Drs. Hilary Llewellyn-Thomas, Ellen Peters, Laura Siminoff, and Dale Collins—addressed the question and provided their rationale during prepared remarks. The moderator, Dr. Michael Barry, then facilitated a discussion between the panelists, with input from the audience, to further explore and add to the various proposed research questions. Finally, Dr. Amber Barnato conducted a simple vote count (see Table 1) to prioritize the panelists' and the audience's recommendations.

Communication and Cancer Care

Communication is a process by which information is exchanged between or among individuals through a common system of symbols, signs, and behavior (<http://en.wikipedia.org/wiki/Communication>, accessed April 12, 2007). The primary objective of communication between patients and health care providers is to facilitate diagnosis and treatment in pursuit of the goals of enhanced quality of life (including reduced suffering) or increased longevity. “Effective” patient-doctor communication can be defined as interactions that convey sufficient information for a doctor to make the correct diagnosis and to suggest one or more evidence-based treatment plans, and for a patient to make an informed decision among alternative treatment plans. For many health conditions, including cancer, the content of communication should include “data” (i.e., information), but also the beliefs, attitudes, and values that may influence a patient's preferences for outcomes and risks of treatment. Tools for accurately measuring effective patient-doctor communication are in their infancy. Nonetheless, considerable evidence suggests that lack of effective

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communication is associated with suboptimal decision making on all levels and with poorer patient outcomes. Conversely, a substantial body of literature indicates that patients who experience effective communication report greater satisfaction with their medical care, lower levels of anxiety and depression, higher levels of understanding about their condition, greater adherence to treatment, and higher overall levels of well-being and quality of life.¹⁻⁴

While health communication is an informational, goal-oriented process, it is also nuanced and emotion-laden. Physicians use communication mainly to obtain what they view as medically relevant information. During this process, they seek to limit social disclosure and focus on what they deem to be “medical”—i.e., biological—information. This occurs because physicians are often uncomfortable with the emotions that attend many medical consultations, and because they are not well trained to pay attention to these types of patient concerns. Most consultations -- even cancer consultations -- are time-limited, and physicians believe that social disclosures are digressions that take valuable time away from the main business of the consultation.⁵ Because of this, patient values and preferences tend to be overwhelmed by physician talk, which typically constitutes at least 60% of a consultation. More often than not, physician talk is tailored to the needs of physicians rather than patients.

Besides the informational and emotional aspects of cancer care communication, there are ethical issues. These include the need to respect patient autonomy, and the likelihood that better communication will lessen the chance of the physician doing harm. Also, of course, any deliberate framing of information on the physician’s part raises ethical questions about manipulating patients’ preferences. A strong case for such manipulation is presented by Sunstein and Thaler, who argue for a program of “libertarian paternalism,” which acknowledges that neutral framing of information does not exist.⁶ The libertarian perspective holds that, while physicians should employ a format that is likely to promote the welfare of the patient, the ultimate choice rests with the individual.

In an ideal world, of course, patients would come to a cancer consultation armed with sufficient knowledge, clarity about their personal values, and the ability to engage in a thoughtful discussion about the pros and cons of treatment options. Providers, in turn, would be prepared to support their patients, armed with an understanding of the patient’s knowledge gaps, his or her personal values about the possible outcomes, and his or her treatment preferences. Unfortunately, this is not easily accomplished given the current time constraints on face-to-face interactions between patients and providers. This is where decision researchers step in.

Decision Research and Cancer Care

The goal of decision research is to advance the fundamentals of decision making with the intention of improving patient care and outcomes. Decision situations in cancer care present an opportunity to provide information to patients, to help them process that information, and, ultimately, to help them make important decisions about cancer prevention, detection, and treatment. In some cancer care situations, the best intervention is clear to both practitioners and patients, because high-quality clinical evidence about outcomes is readily available and the known harms are minimal relative to the benefits. But in cancer care situations that involve unclear clinical evidence, a greater potential magnitude of harm, and more disagreement in patients’ values, the choice among interventions becomes increasingly preference-sensitive. In such cases, the best strategy for a particular patient depends on his or her unique attitudes towards uncertainty and towards the benefit-harm tradeoffs inherent in a particular choice. In cancer care, examples include decisions related to screening (e.g., BRCA1/2), risk reduction (e.g., tamoxifen), and treatment (e.g., watchful waiting, radiotherapy, or radical prostatectomy for prostate cancer).

In short, making good decisions about cancer care can be challenging for both providers and patients. For patients, it requires that they are emotionally ready to make a decision, have sufficient information about the treatment options (along with probabilities of both good and bad results), understand the information and its meaning, and are clear about how the outcomes match up with their individual values. For providers, it requires that they supply high-quality information about the available options, assist the patients in navigating the pros and cons of alternate choices, and help them understand how personal values may affect decisions. In the context of cancer, the interaction can be further complicated by a recent and potentially frightening diagnosis. Given the complexity of the interaction about treatment decisions for cancer, how do we ensure that patients are given the opportunity and support needed to make a high-quality decision? For that matter, how do we determine what constitutes a “high-quality” decision — particularly in preference-sensitive decision situations in which evidence-based medicine or evidence-based reports about the wellbeing of former patients aren’t able to clearly identify a single objective “best” option?

Possible characteristics of good decisions in preference-sensitive situations include clear information processing about issues such as the weight to ascribe to an important variable (e.g., Croyle & Lerman note that individuals underweight the risks of genetic testing relative to their benefits⁷), good overall comprehension, and a close match between patients’ stated values and the chosen option. Sepucha et al. suggest that an assessment of decision quality requires three things: (1) measures of decision-specific knowledge, (2) identification of the patient’s values for the essential outcomes, and (3) an indication of the extent to which the option chosen is consistent with the patient’s comprehension and personal values.⁸

If we can agree that these are the three critical aspects of a decision, then when and how should we measure or document each one? What knowledge does the patient have and need to have? Do we evaluate a patient’s knowledge before the consultation so that the clinician can use the information during the patient encounter, or afterwards as an audit to document that the patient has the required knowledge at the point of decision making? Is it important that the clinician understand a patient’s values for a given outcome or only that the patient is clear about them? Should there be a concordance between the patients’ preferences and their treatment choices and, if so, how do we measure this? These questions are largely unanswered, and there is much work to be done here.

In attempting to address these questions, researchers often assume that patient preferences are stable or can be clarified; this assumption may not always be true. Judgment-and-decision-making research suggests that preferences are often subject to change, depending on the situation in which the decision is being made.⁹ Preference instability leads to “constructed” choices, and a choice constructed from cues present in one situation may be rejected in another situation. This, in turn, can lead to dissatisfaction, system inefficiencies, and serious health and financial consequences for the individual. Recognizing the conditions associated with preference instability is critical, since it is in those decisions that patients likely need the most assistance.

How can we recognize when preferences are stable and therefore helpful to patient decisions versus when they are constructed from salient cues? Possible methods include testing preferences and comprehension across time without obvious changes to information the patient has¹⁰ or across different frames of the same information.¹¹ Other research suggests that preferences will more likely be constructed when decisions are: 1) unfamiliar to the patient, 2) complex (including too much information and conflicting goals), or 3) familiar but not often experienced personally.¹² Preference construction also may be more likely when patients are clear about their values but not about how to make tradeoffs between those values (this may be particularly true with emotionally difficult tradeoffs)¹³, and when

patients lack an affective response to decision options or have different affective responses depending on how options are presented.¹⁴ These conditions imply that preferences are likely to be constructed in the many consequential health decisions involved in cancer care.

Sometimes, health professionals can help patients to successfully clarify their preferences. In cases in which preferences cannot be successfully clarified, we can assist in preference construction and support good decision quality through careful choices about how information and options are presented. Thus, much of the research in cancer care decision making focuses on formalized support tools, among them patient decision aids.

Patient Decision Aids

A patient decision aid is “an intervention designed to help people make specific and deliberative choices among options (including the status quo) by providing (at the minimum) information on the options and outcomes relevant to a patient’s health.”¹⁵ Patient decision aids may also include information about the disease or condition, probabilities of outcomes tailored to personal health risk factors, an explicit exercise to clarify values, information on others’ opinions, and guidance or coaching in the steps of decision making and communicating with others. Finally, patient decision aids can be administered using various media, such as decision boards, interactive videodiscs, personal computers, audiotapes, and audio-guided workbooks.

Most patient decision aids have the objectives of improving knowledge, satisfaction, and participation in decision making, as well as reducing decisional conflict. Reduced decisional conflict means that patients feel more comfortable with their choices and decisions are more congruent with their personal values. A 2003 Cochrane Collaboration systematic review identified 200 patient decision aids, 38 of which had been evaluated in randomized controlled trials and 30 of which were currently in trials.¹⁶ Compared to usual care, patients who used decision aids demonstrated greater knowledge, more realistic expectations, lower decisional conflict related to feeling informed, increased levels of active decision making, and were less likely to have remained undecided after the interventions. However, patients using patient decision aids appeared to do no better or worse in terms of their satisfaction with decision making, anxiety, and health outcomes; patient decision aids also have variable effects on patients’ actual therapeutic choices. These observations hold for the subpopulation of cancer-related decision aids as well.¹⁷

The number of available patient decision aids has expanded rapidly, increasing from 16 identified in 1999 to over 500 in 2004. Concerns have been raised regarding their quality, particularly regarding the mechanisms available for updating patient decision aids with newly emerging information about treatment options, risks, and benefits.¹⁸ This is particularly important in the area of cancer screening, risk reduction, and treatment, because new technologies and treatments promise to emerge even more rapidly in the coming years. A critical effort is now underway to develop explicit quality criteria in the form of the International Patient Decision Aid Standards.¹⁹ Besides determining what information to provide and what media to use, any such effort should also include attention to the following aspects of patient decision aids: clarifying values, teaching deliberative skills, accounting for disparities among patients, and diffusing findings into critical care settings.

Clarifying Values

Methods for clarifying values can be either non-interactive (in which viewers passively receive messages about the important role played by personal values when making a choice) or interactive (in which viewers engage with hands-on exercises that explicitly reveal their preferences).²⁰ Interactive methods, in turn, can be either utility-based or non-utility based.

Utility-based interactive methods employ the standard gamble to elicit a patient's utilities about the possible outcomes of each of the different options, and then fold those utilities into a formal decision analysis to indirectly identify the option with the highest expected utility for that patient.^{21–25} Non-utility-based interactive methods can be either “coarse-grained” exercises that directly reveal overall attitudes towards each option (O'Connor's Leaning Scale), or “fine-grained” exercises that directly reveal attitudes about the specific attributes of each option (O'Connor's Balance Technique and Dolan's Analytic Hierarchy Process).^{26–30}

Even this brief overview illustrates the many fundamental questions facing designers of patient decision aids.^{31, 32} Are non-interactive methods “good enough” or can interactive methods clarify values more effectively? If interactive methods are better, how “coarse-grained” or “fine-grained” do they need to be? How well do they work with different patient decision aid media and at different points in the cancer care continuum? Do different interactive methods reveal consistent or inconsistent preference patterns? Do different values-clarification methods also help with information comprehension or cause more confusion? Do they lower or raise levels of decisional conflict?³³ Do some methods more accurately predict actual choice or lead to greater adherence to the chosen option?^{8, 19}

If patients tend to favor one values-clarification method over another—that is, if they have “meta-preferences”³⁴—and we continue to use a “one size fits all” approach, there are bound to be mismatches between a patient's preferred values-clarification method and the method encountered in a patient decision aid. Mismatches, in turn, could inadvertently generate increased decisional conflict or poor concordance between patients' genuine preferences and the options they actually choose. The overall consequence could be poor decision quality in preference-sensitive cancer care. On the other hand, if we can identify a patient's favored method and then provide an individually-tailored patient decision aid that matches that favored method, we may increase decision quality by fostering true concordance between preferences and choices.^{8, 35, 36}

Teaching Deliberative Skills

Just as studies about the effects of different values-clarification methods could provide fundamental insights into how patients develop informed preferences, studies about the effects of patient decision aids on patients' deliberative skills could provide fundamental insights into how they navigate a series of decisions.

For example, patient decision aids often use hypothetical or former patients' stories to describe different individuals' experiences with different therapeutic options—this on the assumption that such stories help viewers imagine what it would be like if they chose one option or another.^{37, 38} In effect, these stories supplement the objective clinical information provided at the beginning of a patient decision aid. Descriptive research on the experiences of former patients may reveal patterns not only in clinical outcomes but also in experiences, satisfaction, and quality-of-life outcomes. Describing these patterns both qualitatively and quantitatively to current patients who cannot accurately imagine how an unfamiliar health state will affect their lives may assist the shared-decision-making process.³⁹ Although patients cannot always predict what will make them happy⁴⁰, we may be able to help patients who share common experiences to clarify their preferences by providing evidence-based information about the likelihood of outcomes and about how outcomes such as satisfaction and quality of life were experienced by patients similar to them.

However, if viewers don't personally identify with the people in the stories, patient decision aids may inadvertently push viewers' choices one way or the other. Also, presenting a fully “balanced” set of patient stories in a patient decision aid may inadvertently affect viewers'

choices in invalid ways. For a fully balanced set, the patient decision aid should present a story for each possible combination of the positive/negative attributes of a particular treatment process and the positive/negative outcomes for that treatment. Therefore, a two-option situation involves eight patients' stories. Clearly, this places a heavy information-processing load on the viewer, who also may be influenced by the sequence in which the patient decision aid presents positive and negative aspects of the stories. Furthermore, in attempting to present a "balanced" roster of stories, the patient decision aid may over-represent relatively rare negative outcomes or under-represent common positive outcomes, which, again, can inadvertently bias the viewers' choices.⁴¹

One way to side-step these problems is to deliberately design these stories to achieve a *different* objective—namely, to teach viewers about deliberative skills rather than merely provide information about patients' experiences with the clinical options. Cancer patients in particular encounter numerous and successive decision "cross-roads"—about prevention, screening, early diagnosis, initial treatment, follow-up care, diagnosis and treatment of recurrence, diagnosis and treatment of metastases, and palliative care.²⁰ Patient decision aids used at the earlier cross-roads could be explicitly designed not only to help patients address the choice to be made at that particular cross-road, but also to teach them the deliberative skills needed to negotiate their way through relevant information, to clarify their values, to sort out social influences, and to form an action plan.⁴² These enhanced deliberative skills could then be later called into play at new decision cross-roads.^{35, 36, 43–49}

This teaching strategy would take advantage of the interactivity of computer-based or web-based media. For a particular decision situation, a patient decision aid could first present core objective clinical information about the disease and its treatment options, then invite the viewer to select simulated "case descriptions" of three socially matched "patients" (say, Patients X, Y, and Z), who all are of the same sex, age, and ethnocultural background as the viewer. Then, a story could be presented for each of the selected socially matched "patients." In effect, the stories would teach the viewer about the key deliberative steps in decision making, by describing how Patients X, Y, and Z undertook these steps and the different deliberative styles they used for sorting out social influences, and for forming an action plan.

In this longitudinal approach, we could design patient decision aids not only to provide decision support at a particular cross-road, but also to help patients gain deliberative skills that they could later apply to new challenges at new decision cross-roads. We could test the relative effectiveness of this new kind of patient decision aid on patients' downstream skills in dealing with information, formulating and reporting preferences, dealing with social influences, and developing workable plans. If we could identify how best to create patient decision aids that foster enduring transferable skills in deliberative decision making, we could then proceed to test hypotheses about whether these transferable skills lead to outcomes such as increased decision quality. These investigations would be immediately relevant in the kinds of preference-sensitive decision situations that unfold across the trajectory of health care in oncology.

Accounting for Disparities

Certain segments of the population are at greater risk than others for suboptimal communications. These include members of minority communities and individuals with lower educational attainment and/or fewer economic resources. Issues of preference construction may matter even more for individuals who already struggle within our health system and with health information. Different decision aids may be needed to best support the decisions of people who differ in socio-economic background, age, reading literacy, and numeracy, among others. Decision aids that are tailored to the needs of individual patients

can help ameliorate poor communication processes and should therefore be a standard of good care, especially for patient populations facing life-threatening illnesses such as cancer. Research efforts should specifically focus on targeting these patients.

Although the exact relation between literacy and health is unclear, literacy differences have been associated with higher health care costs and may be a driver of health disparities.⁵⁰ Cancer also is generally a disease of older adults. Older adults process information in different ways than younger adults, including having less ability to understand information presented in tables and charts.⁵¹

In addition, a significant percentage of the American population is innumerate, and numeracy tends to be lower in populations with less education and greater age. Based on the National Adult Literacy Survey, about 50% of Americans lack what are considered the minimal mathematical skills needed to make use of numbers embedded in printed materials.⁵² Lower numeracy has been linked with reduced comprehension and a greater influence of less relevant sources of affect and emotion in health decisions.^{53–55} Results of ongoing studies suggest that individuals who differ in numeracy need different kinds of decision aids. Health literacy is not only about the individual patient and his or her ability, but also about the format of the provided information and what it requires from patients. Low levels of patient numeracy are associated with difficulty using quantitative data when making decisions about the risks and benefits of screening mammography.⁵⁵ Woloshin, Schwartz, and Welch have created a primer to teach patients about numerical concepts in health care (e.g., relative versus absolute benefit or risk), so that patients are better able to make a good decision based on the available evidence.^{56, 57} More work like this is essential to ensure that all patients have the resources needed to make health care decisions. The issue of disparities involves not only the ability to process information but even the likelihood of receiving it in the first place. One study of early stage breast cancer patients has reported that the lower the income and educational attainment of the patient, the more likely they are to receive less information about all aspects of their illness and treatment. These individuals tend to ask fewer questions and to exhibit less involvement in the consultation overall. Patients who are members of minority groups also demonstrate these same suboptimal communication patterns.⁵⁸ These patterns of poor communication may be one factor contributing to poorer health care outcomes that have been demonstrated in these populations. It has been suggested that poor communication undermines the patient's ability to convey problems and the physician's ability to make sense of patient concerns. This, in turn, can lead to delayed diagnoses, inappropriate or undertreatment, and nonadherence.^{59, 60} Clearly, communication in cancer care affects decision-making at all stages of the disease from diagnosis through end-of-life care.

Disseminating Decision Aids

In addition to concerns about the quality of existing patient decision aids are concerns regarding the potential harm—or, at least, the reduced effectiveness—of prematurely disseminating such aids without understanding some of the fundamental issues underlying the processes of patient decision making. On the other hand, pragmatists may feel that delaying dissemination of existing patient decision aids into clinical practice is an abdication of the profession's responsibility to move away from paternalistic models of care and towards a patient-centered model that emphasizes informed decision-making.

Despite disagreement about timing, however, all would agree that supporting patient welfare through the use of good quality decision aids requires successful dissemination of those aids, including providing the right tool to the right person. Therefore, research on patient decision aids should include developing cost-effective and feasible mechanisms for disseminating those decision aids into daily clinical practice.

Unfortunately, most researchers working in this area are not trained in the techniques of how to efficiently diffuse the products of our research into clinical practice. Without this final step, the fruits of our research will fail to reach most health care consumers. Therefore, developing and understanding the mechanisms for diffusing decision support tools into practice becomes a high priority.

Conclusion and Recommendations

Despite the introduction of communication training into the medical school curriculum, we have not been especially effective in training physicians to be outstanding communicators. Consequently, many clinicians, especially physicians, still do not fully appreciate the importance of this aspect of providing excellent care to patients. Therefore, we need to build research strategies that specifically target the communication process vis a vis decision making, that disseminate knowledge about the importance of communication, and that lead to the creation of tools to help improve communication.

With these considerations in mind, we recommend the following specific priorities in the areas of basic and applied research.

1. Llewellyn-Thomas:

- To conduct fundamental studies about the effects of using different values clarification methods in decision aids for patients with cancer.
- To conduct fundamental studies about using decision aids to help cancer patients transfer learned deliberative skills to new decision points in the trajectory of care.

2. Peters:

- To study the conditions under which patient preferences are stable, are unstable but can be clarified, or are unstable and will be labile.
- To conduct fundamental research on how to best present information to individuals who differ in abilities, tendencies, and preferences for information processing that are potential drivers of health disparities.

3. Siminoff:

- To better understand and more explicitly incorporate the role of communication in health care decision making and how communication at all levels affects health care outcome disparities in the following populations: (a) minorities; (b) older patients; (c) low SES patients.
- To develop mechanisms to diffuse the use of decision support tools into clinical practice that can enhance communication or attenuate the impact of poor communication practices.

4. Collins:

- To define, capture and communicate critical aspects of a decision for use in the clinical encounter.
- To develop methods and tools to help patients become better decision makers, not for a single, specific decision, but over the course of an illness and throughout their lives.

These recommendations are intended to be complementary rather than competitive. Clearly, there are many basic and methodological questions that still need to be answered regarding issues in decision making about cancer care, and different researchers are bound to set

different priorities. However, for clinicians who routinely work with patients facing difficult decisions about the treatment of cancer, the top priority is clear: to find methods and tools that can directly help patients make sound decisions during this difficult time in their lives.

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Table 1

Basic/applied research priorities: a vote count

Type	Research Priority	Votes (%) [†] (N=117) [‡]
Basic	To conduct fundamental research to identify and attempt to attenuate the impact of individual differences in abilities, tendencies, and preferences for information-processing that are potential drivers of health disparities. (Peters)	26 (22%)
Applied	To better understand and more explicitly incorporate the role of communication in health care decision-making and how communication at all levels affects health care outcome disparities in the following populations: (a) minorities; (b) older patients; (c) low SES patients. (Siminoff)	25 (21%)
Applied	To develop mechanisms to diffuse the use of decision support tools into clinical practice that can attenuate the impact of poor communication practices. (Siminoff)	14 (12%)
Applied	To understand how patients prioritize information. (Audience)	14 (12%)
Applied	To develop methods and tools to help patients become better decision makers, not for a single, specific decision, but over the course of an illness and throughout their lives. (Collins)	10 (9%)
Basic	To explore the distinction between static cross-sectional decisions and longitudinal, dynamic decisions. (Audience)	10 (9%)
Basic	To conduct fundamental studies characterizing conditions under which patient preferences are pre-existing and stable and therefore can be successfully elicited versus those conditions when preferences are unstable. (Peters)	9 (8%)
Basic	To conduct fundamental studies about using decision aids to help cancer patients transfer learned deliberative skills to new decision points in the trajectory of care. (Llewellyn-Thomas)	6 (5%)
Applied	To define, capture, and communicate critical aspects of a decision for use in the clinical encounter. (Collins)	6 (5%)
Applied	To explore the role of patient decision aids in helping potential subjects decide whether or not to enroll in clinical trials. (Audience)	3 (3%)
Basic	To conduct fundamental studies about the effect of using different values clarification methods in decision aids for patients with cancer. (Llewellyn-Thomas)	1 (1%)

[†]Numbers may not sum to 100 due to rounding;[‡]Approximately 40% of the audience submitted a ballot.