

Patient agency in the rhetoric of health decision guides

by

Mary B. Duerson

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Program of Study Committee:  
Diane Price Herndl, Major Professor  
Rebecca E. Burnett  
Peter F. Korsching

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Graduate College  
Iowa State University

This is to certify that the master's thesis of  
Mary B. Duerson  
has met the thesis requirements of Iowa State University

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## Chapter 1

### Introduction

Some patients have the ability to do extensive research on their medical conditions and interpret evidence-based medical literature, but those who do not are more likely to rely on their doctors for information or to seek it from patient education materials. Either course of action can be problematic. Medical choices can be difficult, and doctor consultations and patient education materials often do not make them less so. Because uncertainty about risks and benefits of treatments make decisions complex, patients often rely on medical advice (Griffiths 469). But as a study reported in the *Journal of the American Medical Association* shows, that is not always the most objective source because specialists tend to recommend the treatment that they specialize in (Fowler et al. 3217),<sup>1</sup> nor are physicians a complete source, as another study in the journal reports that they often lack patient information—important information is not available in one of seven visits (Smith et al. 565). This same study showed that health decision guides downplay the negative aspects of treatment choices. A study led by Angela Fagerlin and others looks at such guides for just one disease—early-stage prostate cancer—and highlights the complexity of medical decisions and the weaknesses of some guides. With this disease, the main treatment options are surgery, external radiation, internal seed implant radiation, and watchful waiting, with no proven difference in mortality rates (American Cancer Society n.p., Eng et al. 239). Once patients grasp this concept, which often is not clearly explained in guides<sup>2</sup> (Fagerlin et al. 721), in

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<sup>1</sup>According to this study, urologists recommend radical prostatectomies (surgery) to their patients, and radiation oncologists recommend radiation.

<sup>2</sup>Only 37 percent of print materials and 37 percent of Web sites described the lack of conclusive evidence about which treatment has the best outcomes and cure rate (Fagerlin et al. 725).

order to make an informed decision about their treatments, they need to know what side effects and other risks are associated with each option.

Many health care institutions have developed materials to help people with cancer better understand their disease and make decisions about their treatments, but often they do not provide what patients need (721). According to the Fagerlin study, they are lacking in the following ways:

- They don't offer complete information about treatments and their side effects.
- They don't offer enough quantitative information.
- They are written at an inappropriate reading level for the average U.S. adult.

(727)

I would also argue that they do not factor into the decision-making process the social, psychological, and emotional consequences of cancer treatment; they do not acknowledge patients' knowledges and standpoints; and they do not address the patients' varied attitudes toward risk and uncertainty, power, and decision making.

If patients cannot get an objective answer from their doctors, and health decision guides leave them with the kind of uncertainty that comes with data overload, or worse, incomplete information or inattention to key factors in the decision-making process, developers of health decision guides have a responsibility to improve their products. In their book *Evidence-Based Patient Choice: Inevitable or Impossible?* Adrian Edwards and Glyn Elwyn say that to be useful, such guides must be accessible, comprehensible, and tailored to their audience and that "critical evaluation of them is as important as critical evaluation of primary research literature" (201). I would add that more than evaluation, we need to re-envision these guides in a broader sense in a way that genuinely fosters patient agency.

The primary goals of this thesis are

- to re-envision health decision guides in light of rhetorical and feminist theory in such a way that the potential of this genre for facilitating patient agency and improving physician-patient communication is realized and
- to increase our understanding of the patients faced with medical treatment choices and the problems of medical writers in creating guides that will be useful in real-world decision-making situations.

One other benefit of studies such as this, according to science rhetorician Alan Gross, is to increase “scientists’ awareness of the rhetorical component of their communicative practice” (63). Recognition of the central role rhetoric plays in medical discourse, like the role it plays in science generally, has been slow to evolve—not only in health care but also among medical writers and rhetoricians (Barton; Bell, Walch, and Katz). In this thesis I try to point out the rhetorical nature of health decision guides and apply a rhetorical perspective to this type of health communication. Very little of the wide range of research on health communication takes this approach (Specker Stone, 202, 215; Segal 1994, 91). This paper takes up Beverly Sauer’s suggestion to explore “the deep and complex . . . way texts enter into . . . systems of material and social [and scientific] practice” (Bazerman 2003, xviii). Decision guides are one such text in medical discourse that developed in response to exigencies in the health field but also are playing a role in its continued evolution. They have the potential to help patients recognize that the expert knowledge they have of their own values, experience, and situation is vital to making informed decisions in conjunction with the biomedical knowledge and clinical experience of their physicians. And as a sort of boundary object between the biomedical world and patients’ life worlds, this type of guide has the ability to affect patient-doctor relationships and facilitate patient agency.

My argument takes the following form: In chapter 1, I give an overview of what historical exigencies health decision guides are a response to and offer the research questions that will guide this study. In chapter 2, I review how others have used feminist and rhetorical theory to inform health communication research, and I summarize aspects of rhetorical audience theory and feminist theory that might be put to use in our re-envisioning of the genre. In chapter 3, I show the results of a rhetorical analysis of one health decision guide with respect to the author's approach to audience, rhetorical appeals, and patient agency. And in chapters 4 and 5, I make recommendations for re-envisioning and improving health decision guides and offer suggestions for future study.

### **What are health decision guides?**

Health decision guides are a form of patient education materials produced by doctors and health information professionals for people facing life-changing medical choices. The goal of health decision guides would seem to be to empower people to take a more active role in treatment decisions by giving them enough evidence-based information so that they can balance harm and good in their decisions at a reasonable cost. Health decision guides are available in print format, on web sites, in videos and multimedia CDs, and so on. Each guide usually focuses on one disease or condition, or sometimes just one stage of a disease. It generally includes sections on the disease pathology, signs and symptoms, diagnosis, and treatment.

### **Studies of the genre**

These guides have taken shape in response to doctors' perceptions of what patients need and, to a degree, available research on audience analysis, reader surveys, and usability

studies (e.g., Turns and Wagner, Albers and Mazur, Freeman and Spyridakis, Rozmovits and Ziebland, Fagerlin et al.). Even so, partly because many of the research findings have not been put into practice yet, such guides have a great deal of room for improvement, and much remains to be learned about their actual effect on the outcomes of decisions and on health care costs.

In brief, let me explain what a few of these studies have done, what they have concluded, and what they do not accomplish. Angela Fagerlin and her colleagues did a comprehensive content analysis of 546 patient education materials on early-stage prostate cancer and found that they lack comprehensive information about risks and benefits of each treatment. Linda Rozmovits and Sue Ziebland surveyed prostate and breast cancer patients on how satisfied they are with Internet-based health information and reported that patients saw pitfalls in using health information from the Internet. When they do use it, they preferred to trust sites maintained by universities or well-known medical centers, but even so tended to cross-check information from several sites rather than rely on one source. A report by Liberatore and his colleagues summarized findings from other literature on decision aids: "In general the aids are well accepted by patients when they can be accessed easily. In addition, they tend to increase patient knowledge, provoke little or no patient anxiety, reduce decisional conflict, and foster interactions between practitioners and patients relative to decision making. It also appears that exposure to decision aids may improve patient outcomes" (4). Several studies have focused on the role of technology in presenting this type of information. Albers and Mazur, in their book *Content and Complexity*, address issues of web-based information design for complex problems and point out that good information is of little use if the document producers do not also understand the user goals and needs, the information in context, and the situational context. Their goal is to use web design



technology to support complex problem solving rather than mere “information look up” (279). Turns and Wagner present a case study of audience analysis of the web site Arthritis Source, an information web site originally developed at the University of Washington. They offer various strategies for how to learn about a site’s audience and use that knowledge to revise the site. They analyzed six dimensions for characterizing audience: user role (e.g., patient, caregiver, or medical professional), goals, knowledge (what do users know, how do they know it, and what is the quality of their knowledge?), human factors (the users’ perceptual and physical skills and abilities), circumstances of use, and culture. They highlighted that the work of audience analysis and incorporation of that information into information design is ongoing, not just a start-up task. Freeman and Spyridakis also examined on-line health information, particularly the factors that affect the credibility of a site.

Studies have also shown that health decision guide readers are different from readers of scientific writing for the general public. Rather than reading for pleasure, they are driven by a need to know more in order to cope with a health condition or illness. One study looks specifically at what cancer patients want from health decision guides. In a series of interviews, a large group of people with breast or prostate cancer said that they are looking for information that is credible and personally relevant (Rozmovits and Ziebland 57). Some are seeking connections with and advice from other people who have their type of cancer. Some want up-to-date, easy-to-understand information about treatments and side effects, more quantitative information, and reliable information from an unbiased (noncommercial) source (Fagerlin et al. 726, Rozmovits and Ziebland 57). In addition, these patients said that for a decision guide to be truly useful, it should help them determine what value they place on certain benefits and risks (Fagerlin et al. 724). Because cancer patients who visit health

information web sites are seeking information and support, we can be fairly certain that they are embracing the concept of informed decision making. Support for this type of guide can also be found in Sauer's summary of the findings of risk communication researchers: "[Lay audiences] want to develop competence so that they can formulate their own opinions about future options [or at least prepare for a physician consultation]. If they know nothing, risk communications will be incomprehensible" (2003, 13, n. 29). A well-informed patient will be better able to talk with a physician when he or she tries to explain what is happening and why, and what is possible and what is not.

Research has shown that decision aids improve patient participation in decisions and patient satisfaction with decisions after treatment is completed (Edwards and Elwyn 226). Even in situations of uncertainty, when people take an active role in making decisions about their treatment, they are more likely to feel better about it, have a better sense of control and less anxiety, feel more able to cope, and be more able to talk about their disease and its effects with loved ones (Wong et al. 13). The study by Fagerlin and colleagues said that such guides can be especially helpful

- when treatment options have major difference in outcomes or complications,
- when decisions require trade-offs between short-term and long-term outcomes,
- when one of the choices can result in a small chance of a grave outcome, and
- when there are marginal differences in outcomes between options.

(721–728)

Other reviews of decision aid research have called for "the use of rigorous research designs that are based on theory, include meaningful process and outcome measures, and serve to identify interventions that can facilitate practitioner-patient interaction" (Liberatore et al. 1423). Communications researcher C. M. Coley, in discussing prostate cancer screening in

particular, says that no guides help patients to systematically consider the complex information related to screening decisions, pros and cons of behavioral alternatives, and values-based decision making (quoted in Liberatore et al. 1423). Finally, little is known about the effect of such guides on knowledge, attitudes, behavior, and effectiveness related to outcomes and costs. Interesting work is increasingly being done comparing outcomes of men who make decisions based solely on doctor consultations with those who used a variety of patient education materials.

### **Development of the genre**

In the late 1990s, most decision aids were for common conditions with strong evidence-based research and clear choices, such as cardiovascular disease and diabetes. Increasing recognition by health information professionals of patients' desire for such guides and demand from patients themselves have led to the development of more guides covering a wider range of conditions, including those with less clear-cut choices, which are thus, in theory, more dependent on patients' values related to outcomes. The rapid growth in production of health decision guides is also a response to the evidence-based practice movement and the informed-choice movement. Both of these have been driving deep and pervasive change in the medical world, change that is part intellectual (evidence-based practice) and part social (informed patient choice and its effect on the patient-doctor dynamic). David Eddy, in *Medicine, Money, and Mathematics* comments on what may have been driving the shift toward evidence-based practice: "Methods of reasoning and problem solving that might have worked well in the past are not sufficient to handle today's problems" (quoted in Irwig, Irwig, and Sweet 26). He says the informed-choice movement challenges the long-held notion, "Doctor knows best." Whereas previously patients might

say, “Why do I need to read anything—surely a qualified doctor would know what’s best” (26). Now many say, “I’ll find out all I can, listen to the doctors [note the plural, reflecting an increased willingness to gather second and third opinions], ask questions of doctors and others, then decide for myself.”

### **What is the informed-choice movement?**

As mentioned, one impetus behind health decision guides has been the movement toward informed patient decision making (see Hope, Herxheimer et al.). I think informed choice has come to be accepted as the best course for Western medical practice, but it has not always been so. Previously, the benchmark was informed consent, which amounted to the patient agreeing with the physician’s question, “Do you trust to me to make the decision for you?” Now after years of health activists’ increasingly louder mantra of informed choice, the expected mode of behavior for physicians is to move from “paternalism to being a partner in their patients’ decisions” (Irwig, Irwig, and Sweet 39), and the role of patients has become more active. In a review of the book *The Resourceful Patient*, by Muir Gray, Chris Del Mar makes a call for patients to become “resourceful, accept responsibility for their own health care, and form partnerships with their doctors” (168). Not all patients embrace this active role in their care, and not all doctors believe in truth-telling—the patient’s need for information in order to make decisions. The authors of *The Biopsychosocial Approach* say that this type of attending physician “was raised in a more paternalistic era, and believed there were circumstances when the truth should be withheld” (Frankel, Quill, and McDaniel 260). They report that a review of literature shows that “truth-telling among American physicians is a relatively modern phenomenon”—a remarkable change from about 5 percent in 1967 to 95 percent in 1979 (260).

The rapid development of health decision guides was spurred on by the philosophy voiced by Natalie Angier and other patient advocates: “A choice has meaning only if it is freely and knowingly embraced, with all the risks, benefits, and alternatives honestly arrayed before the chooser. . . . To make a truly informed choice, we need information” (118–120). Some would say it is the moral obligation of physicians to give people information and choice. In some states this obligation has been codified. During the so-called breast cancer wars of the 1970s and 1980s, patients and a few doctors challenged the status of radical mastectomy as the primary treatment option for women with breast cancer and demanded that scientists research and offer to patients other choices, such as lumpectomy. Some states passed laws mandating that breast cancer patients be informed of all treatment alternatives. This publicized the issue of informed choice for other diseases too (Lerner 232).

It took quite some time for the medical community to recognize that “patients are entitled to make their own decision about medical treatment and procedures and should be given adequate information on which to base those decisions” (Irwig, Irwig, and Sweet 40). Barron Lerner, in his book *The Breast Cancer Wars*, writes, “The loudest critics of informed choice were the doctors: They were resisting outside influence on their patient-doctor relationship. Doctors were not neutral in this so-called war” (233). The debates continued into the 90s (240).

The breast cancer wars were themselves spawned by the science wars of the 1970s, which heralded a change in American public values. People “began to reject the long-standing presumption in favor of science and technology” (Miller 2003, 168). They “disputed the inevitability of a gap between the knowledge of scientists and that of the public,” and these debates closed “an era of rapid growth and almost unquestioned faith in expert opinion”

(Bensaude-Vincent 102)<sup>3</sup>. Miller quotes Roger Cooke (*Experts in Uncertainty* [New York: Oxford University Press, 1991]) in noting that “the percentage of Americans with ‘great confidence’ in the leaders of a variety of institutions (medicine, education, religion, industry, and others) declined sharply between the mid-1960s and the early 1970s and points to the war in Vietnam as a significant factor in this change” (2003, 189–190). People began to dismiss the idea that doctors necessarily make decisions for patients and that science has all the answers.

You can see how the informed-choice movement was long in evolving because as late as the 1990s doctors expressed concern for the erosion of doctor authority, as indicated by these medical journal article titles: “Shared decision making in the medical encounter: What does it mean?” “Patient participation and decision control: Are patient autonomy and well-being associated?” “Empowerment of men newly diagnosed with prostate cancer,” and “Increasing patient involvement in choosing treatment for early breast cancer.” As little as six years ago, the *Journal of the American Medical Association* was still trying to make the case for informed patient choice, presumably because it had an audience of resistant doctors:

Increasingly clinicians are being encouraged to involve patients in their medical decisions, both diagnostic and therapeutic. Such shared decision making is particularly important when the optimal management strategy depends on the strength of patients’ preferences for the different health outcomes that may result from the decision. In such a circumstance, the optimal strategy may be quite different for two patients with different preferences facing the same decision. (Braddock et al. 2313).

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<sup>3</sup> See Bensaude-Vincent for a multicentury overview of the relationship between science and the public, knowledge and opinion. It ends with support for the resurgence of the Enlightenment view of the role of public opinion in shaping the scientific endeavor and agenda.

Since the 1990s, many patients have become more empowered health care decision makers, more actively involved in treatment decisions, and more adept at finding available information, sometimes having access to the same resources as doctors (via Medline, Science Direct, and so on). And many doctors are willingly accepting patients as co-decision makers. For both doctors and patients, “Decisions aids are becoming increasingly popular as a way of conveying and discussing information about treatment options” (Edwards and Elwyn 198).

### **What is the evidence-based practice movement?**

Another force behind the growth of health decision guides was the evidence-based practice movement. Health decisions are more complex than ever, and doctors cannot be expected to know how to handle every problem based on their limited clinical experience. This fact fueled the evidence-based medicine movement, in conjunction with patients’ desire to rely on something more than doctors’ word and intuition and patients’ growing desire for solid information in the face of uncertainty. It gained momentum in the early 1990s, when people tried to close the research-practice gap. At this time, “The ironic suggestion that health care decisions should be based on ‘evidence’ was at the same time a novel and contested process in medicine” (Edwards and Elwyn 5). This movement claimed that treatment decisions should be based on proved treatments not just on doctors’ knowledge of disease pathology and clinical experience (often gathered into printed clinical practice guidelines as representative of an expert body of knowledge). Judy Irwig and her coauthors point out that many such guidelines “are based on a consensus of expert opinions rather than on a search of unbiased evidence. This approach is not reliable, no matter how valid the views appear or how eminent the experts involved. The advice of confident experts, which

form such consensus guidelines, has a history of later proving to be misguided” (65)<sup>4</sup>. They say that such guidelines tend to underestimate risk and overestimate benefits (10–11). For example, radical mastectomy was long the accepted treatment for breast cancer. It took a long time before trials were conducted to explore whether less drastic treatments would be just as effective. Other examples of once-accepted-but-unproved (and now abandoned) practices are the routine removal of tonsils in children and the use of x-rays on pregnant women to judge pelvic size.<sup>5</sup>

In contrast to the way such clinical practice guidelines were developed, “The authors of evidence-based guides research the evidence from medical literature and appraise its credibility “in a way that most practitioners simply do not have the time or expertise to do” (Irwig, Irwig, and Sweet 65). Evidence-based medicine “seeks to shake professionals from paradigms of practice that are not proved to be of benefit to patients or that carry unacceptable risks” (Edwards and Elwyn 98). Doctors resisted this emphasis on evidence-based practice guidelines because “[It] seems designed to make medicine an applied science, no longer an art or craft founded on experience” (78). In addition, Theodore Porter, in *Trust in Numbers*,<sup>6</sup> says that scientists “tend to resist having their discretion limited by being forced to use calculative models” (quoted in Miller 2003, 196). But the trend persisted because “decisions based on formal method, on numbers and algorithms, are perceived to be both fairer and truer than those based on experiential judgment because their impersonality is

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<sup>4</sup>And as Diane Price Herndl states in her book *Invalid Women*, even though “the American Medical Association presents a public front of unity, in fact the medical discourse is at odds with itself and with other discourses. Meaning is not created through a single voice but in the interaction of voices, in dialogue. It is always a discourse-in-progress” (1993, 14).

<sup>5</sup>Sandra Harding says this is inevitable. “The standards of modern science have historically changed over time and are always rhetorically constituted and deployed. . . . [They] have an integrity with their historical era” (2000, 253). So even though evidence-based medicine may seem better, it too is imperfect.

<sup>6</sup>Subtitled *The Pursuit of Objectivity in Science and Public Life* (Princeton, NJ: Princeton University Press, 1995).



interpreted as objectivity. Porter characterizes the move toward methodized decision making as our “trust in numbers” (200)<sup>7</sup>.

### **Limitations of evidence-based medicine**

Evidence-based practice, just like the traditional intuitive and clinical practices before it, is still accompanied by uncertainties. Even with the availability of evidence-based medicine, “In some cases health care choices are indistinct” (Edwards and Elwyn 196). Evidence-based medicine is not wholly embraced by some because it gives an illusion of certainty that just is not there. The reasons for the limitations of evidenced-based research are many.<sup>8</sup> Well-known science writer Victor Cohn points out that all studies have flaws, but some have more than others. Even those in respected medical journals are victim to “shaky statistics and lack of any explanation of such crucial matters as patients’ complications and the number of patients lost to follow-up” (11). The result, according to Gary Friedman of the Kaiser organization’s Permanente Medical Group, is that “Much of health care is based on tenuous evidence and incomplete knowledge. . . . Seemingly authoritative statements and accepted medical doctrines, perpetuated through textbooks and lectures, often turn out to be supported by the most meager of evidence, if any can be found” (quoted in Cohn 11). In short, uncertainty is just as much a part of medical practice as it is of other areas of life.

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<sup>7</sup>Porter points out “the increasing replacement of expert judgment with quantified or formal decision methods over the nineteenth and twentieth centuries in both Europe and the United States,” a trend that he characterizes as a “response to political pressures, a bureaucratic ‘strategy of impersonality’ adopted in ‘conditions of distrust’ when decision makers have neither the power nor the presumption to ensure that decisions will not be challenged” (Miller 2003, 196).

<sup>8</sup>“Lack of funds to mount enough trials; lack of enough patients at any one center to mount a meaningful trial; the expense and difficulty of doing multicenter trials; the swift evolution and obsolescence of medical techniques; the fact that, with the best of intentions, medical data—histories, physical examinations, interpretations of tests, descriptions of symptoms and disease—are notoriously inexact and vary from physician to physician; the serious ethical obstacles to trying a new procedure when an old one is doing some good, or to experimenting on children, pregnant women, or the mentally ill” (Cohn 10).

### **Purpose of health decision guides: Persuade, inform, or guide?**

Because doctors and patients have different understandings of uncertainty, the purpose of health decision guides is sometimes not clear. In response to uncertainty (which in doctors' case might mean several things: incomplete or bad data, insufficient knowledge, and inadequate technology), doctors qualify, hedge, and seek more and better technology (Babrow, Kasch, and Ford 11). To them uncertainty is primarily related to outcomes and potential side effects. In response to uncertainty, doctors also use a blend of clinical decision analysis (based in evidence-based medicine, including quantitative judgments about probabilities) and art (the traditional practice of medicine based on doctor's clinical pathology knowledge, experience, and intuition). But they are also the first to recognize uncertainty as something people simply have to accept.

Patients' response to uncertainty (which to them generally means mental confusion that results from either the lack of information or the overwhelming amount of information available and the awareness that the quality of information is often suspect) is to seek knowledge and clarification. To them, the final authority is information, and their decisions will be made in partnership with their doctors. A main difference between what doctors mean by knowledge and what patients mean is that patients seek knowledge from a variety of sources, including from within themselves and from the stories of other patients,<sup>9</sup> and doctors judge knowledge to be that which is available in the literature and that which they or other doctors have gained from clinical experience.

Health decision guides must take into account these varied understandings of risk and knowledge and try to shape their purposes based on the expectations of both physicians,

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<sup>9</sup> Stories may be unreliable but useful (Irwig, Irwig, and Sweet xvi).

patients, and those who produce such guides. As Ann Blakeslee says in *Reshaping Technical Communication*, “Single texts can function as different genres in two settings” (2002, 50). In the patients’ homes, health decision guides function to decrease patient uncertainty and to prepare them for the patient-doctor interview. In the doctors’ offices, reference to such guides may have two very different effects—making doctors bristle or making them more willing and able to discuss options with their patients. By helping patients talk to doctors in their language and by validating their own embodied knowledge,<sup>10</sup> they help to facilitate a shift in the patient-doctor relationship from the traditionally hierarchical one. Patients might expect such guides to inform and give them a voice in creating sense of the facts in light of their own values. Producers of the guides want both to inform or entertain, within the constraints of time and money typical of such publishing endeavors. Doctors’ purposes and motives are just as varied—they may want to gain the cooperation of patients, promote themselves as experts, facilitate shared decision making, or persuade (“induce others to submit to [their] ideas” [Bazerman and Prior 4]). Perhaps it is not possible to separate persuading from informing. Health decision guides are “highly rhetorical documents and the information landscape presented is shaped by the goals and the needs of the agencies preparing the documents” (Bazerman, Little, and Chavkin 467). Even in the literature that the writers select for interpretation, they are making rhetorical choices—they base their decisions on the ethos of the journal, size of the study, whether a claim is made by more than one study, and so on. They use a variety of medical literature, some conflicting, which itself was the result of peer review in which “authors, editors, and reviewers together transform the raw

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<sup>10</sup>The term *embodied knowledge* conveys the idea that we each carry in us our history, our materiality. We are not merely reproduced, radically individual objects. Feminist scholar Nancy Chodorow says that through the relationship between the self and place, structured places get embodied by humans. We are not merely biological or social but reciprocal and embodied. Because of this, rather than authority lying with the individual, it lies with our radical interconnectedness (see Chodorow 14–15).

material of manuscripts into the finished product of validated knowledge claims, that is, how they convert research resources into new knowledge” (Berkenkotter and Huckin 61).

Similarly in the editorial process of health decision guides, when a manuscript is reviewed and doctors disagree on which medical literature should be referenced or which procedure recommended, a testily cordial discourse ensues with an undertone of agonism and territorialism, not unlike that in peer review. This discussion consists of a set of negotiations among author, reviewer, and editor, each of “whom draw on previously established generic conventions and argumentative moves” (63).<sup>11</sup> Health communication scholar David Nelson and his co-researchers recommend that in situations of dissensus like this, more information is better than less: “When scientific consensus does not exist on a specific topic, when there are potentially serious side-effects involved, or when personal values are critical to a decision, it may be more appropriate simply to present the information but allow individuals to make informed decisions on their own” (14).

Health decision guides can help patients to confidently take on the role of co-agents in their health care. Some patients want to know as much as possible about their condition, some do not. Some want to make all the decisions; some cede that power to their doctors. Decision guides seem to be designed for those who fall between these two extremes. Decision guides cannot provide the level of detail that medical literature can; they cannot duplicate in the patient the doctor’s biomedical knowledge. Nor can they provide the best, most personalized advice obtained in a patient-doctor consultation. Because of this, health decision guides are best used to prepare the patient for that medical interview. Herein lies their potential for affecting patient-doctor relationships. These aids can help place the doctor

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<sup>11</sup>In fact, a close look at Mayo Clinic’s book and web site products will show that the production processes of each have resulted in different recommendations related to treatment of early-stage prostate cancer. Some of these discrepancies may be attributed to the tincture of time, some not.

and patient on more equal footing (Edwards and Elwyn 200). As a type of boundary object<sup>12</sup> health decision guides have the potential to be a mediational tool in the doctor-patient relationship. Because the doctor-patient relationship has traditionally been hierarchical, “it is not always easy for patients to question their doctors—and doctors are not always used to being closely questioned” (Irwig, Irwig, and Sweet 41). The relationship is one of “dialogic incommensurability” (Segal 1994, 94) because they each come to the relationship with a different story—that of medicine or that of a life world. And as Yrjö Engeström and his colleagues point out, “Argumentation is not fruitful if there is no common point of reference” (327). What if we put these two stories together, would the resultant treatment decisions be better? Health decision guides have the potential for giving patients and doctors the shared values and common language for meaningful communication. Such guides can serve as a mediator, a conversation starter, helping to span the communication gap between scientist and public (see Bensaude-Vincent). As such they have a role to play in shared decision making.

Health decision guides strive to enable patients to make informed choices, feel satisfied with their decision, and adhere to a chosen treatment plan. Whether they do or not may be a subject of future studies (Edwards and Elwyn 222). Some studies do show they are successful in

- reducing the number of patients who are uncertain about what to do,
- increasing patients’ knowledge of the problem, options, and outcomes,
- influencing the patient-doctor relationship,

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<sup>12</sup>Defined by Leigh Star as “objects that are both plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across ties. . . . Like the blackboard, a boundary object ‘sits in the middle’ of a group of actors with divergent viewpoints” (quoted in Engeström, Engeström, and Karkkainen 321–322).

- creating realistic personal expectations of outcomes,
- improving the match between choices and patients' values,
- increasing patient agency, sense of empowerment,
- decreasing sense of victimization (by either the disease or the medical system), and
- decreasing levels of patient anxiety and depression related to health care decisions.

(226)

In a 2002 critical review of patient education materials on early-stage prostate cancer, researchers found that 502 of 546 items did not describe all four standard treatments. Of the 19 web sites analyzed, none contained all 54 recommended content elements, the highest having 43, the lowest eight, and the average 27 (Mayo Clinic's guide ranked 10th of 19). Of 62 items closely examined, including print materials, web sites, and multimedia products, only one (a multimedia product on early-stage prostate cancer treatment produced by HealthMark) contained all recommended content elements. If the goal is to offer patients a guide that facilitates informed decision making about their treatment, the lack of adequate materials—materials that keep pace with this ever-changing field and accurately reflects its competing interests—is a serious problem. Researchers have called for “a new generation of materials” (Fagerlin et al. 727).

### **Research questions**

What content studies like these from a health communications approach do not help us to answer is, How can we do it better? The rhetorical analysis in this study may. It may bring me closer to answering my primary research question: **What insights from rhetorical and feminist theories might inform and re-envision the writing, purpose, and shape of health decision guides?** To get to that point, I will first address the following questions:

- How does the author of the health decision guide view audience, and what role does the author assume?
- Considering the author's stance toward audience, does the guide effectively use arguments from ethos, pathos, and logos?
- Does the guide acknowledge the patients' knowledges, attitudes, and standpoints?

Then I will look at the content and structure of the guide in order to arrive at practical recommendations for improvements:

- Might its current structure be blinding us to possibilities that it could be serving?
- What does the genre and its intertextual and contextual features reveal about the norms, epistemology, and ideology of its creators?
- How can decision guides tease out the embodied knowledge (lifestyle, experience, values) of patients, blending with biomedical knowledge to yield optimum treatment choices?

I expect to find that much decision-aid writing leaves out a critical element of decision making—consideration of the patients' values and experience. And I expect to find, as Mary Specker Stone did in her 1997 study of diabetes patient education materials, that the “entrenched language and text conventions of medical professional discourse function to restrain the emergence of patient agency” (203). My bases for a rhetorical inquiry into health decision guides are the rhetorical and feminist studies of risk communication by Beverly Sauer and rhetorical audience theories, both of Aristotle and of contemporary theorists Walter Ong, Charles Bazerman, Ann Blakeslee, and others. In addition, I will draw on feminist epistemology and the standpoint theory work of Evelyn Fox Keller, Nancy Hartsock, and Sandra Harding, each of whom has something to say about how knowledge is

understood and created and how that understanding can work both with and against traditional scientific and rhetorical theory.



## Chapter 2

### Literature Review and Theory

This paper draws on rhetorical and feminist theories to develop an understanding of the interaction of writer, reader, genre, and knowledge assumptions to find a way to re-envision health decision guides as texts that empower patients and improve physician-patient communication. I think that a study of such guides will show them to be based on a traditional biomedical discourse that privileges the physician's voice over the patient's and that devalues or excludes the embodied knowledge of patients, other laypeople, and alternative voices. By examining the underlying assumptions of health decision guides about power, authority, expertise, and health care, I hope to justify my hunch that most health decision guides now do not genuinely foster patient agency and then make recommendations for how such genre deficiencies might be corrected. With this renewed understanding and these recommendations, producers of health decision guides might reconsider, in the light of some aspects of rhetorical and feminist theory, the rhetorical moves and subordinating habits they do use, perhaps to unintended effects. This connecting and reconnecting of discourses might link difference in a way that fosters new understandings between physicians and patients.

I would like this thesis to lead to health decision guides that are more patient centered; more balanced in their appeals to emotions, institutional credibility, and rationality; and less constrained by the conventions of traditional biomedical discourse that reflect positivist, hierarchical, dichotomous thinking. (*Positivist* in the sense used here refers to a way of knowing, an epistemology, that justifies beliefs through observations of the natural world. Part of the postmodern critique of this stance is that because we always bring

preconceptions to our observations, every observation is also only our own egocentric perception, which casts doubt on all empirical knowledge [Price Herndl 2004].) Because science has been particularly resistant to including women's experiences and knowledge, rhetorician Paul Dombrowski cautions that trying to draw connections between feminist theory and rhetorical theory or technical communication will be difficult. But I am encouraged by Sandra Harding, Uma Narayan, and other scholars who have seen and done successful cross-disciplinary studies of this sort. Classical moral theory values discursive equality, openness, and inclusiveness, as does feminist theory. Alison Jaggar says that feminist theory differs in that it directly addresses "issues of discursive equality and openness in situations inevitably structured by power," by which I think she means power inequalities (2000, 2). That may be an especially useful aspect of feminist theory in this study of health decision guides, which could be said to serve as a mediating force or boundary object between two quite disparate worlds—the biomedical world of physicians and the life world of people seeking health care.

To begin, I model a sort of rearticulated theory on Beverly Sauer's combination of rhetorical and feminist theory in *Rhetoric of Risk* (2003), her book on mine safety. This is not an obvious point of departure for this study of health decision guides, but in Sauer's exploration of technical documentation in hazardous environments and the experiential knowledge of miners, she has overlaid the Aristotelian rhetorical dictum to "find out the available means of persuasion" with theories about feminist ways of knowing and the way the privileged, rational (male) "discourses of science and technology reflect silent and salient power structures [political, medical, economic] that deliberately or inadvertently silence the voices of women and others" and "render invisible the kinds of information decision makers need" (4, 5). For my purposes, patients may very well be viewed as those "others" Sauer

refers to. Just as she found that the exclusion of women from mining discourse perpetuates the status quo, patients too are excluded and objectified in such a way that they “internalize the beliefs, myths, symbols, and values that preserve unequal power structures” (1993, 76–77).

In Charles Bazerman’s introduction to Sauer’s book, he says, “Mines and mining are more real and complex and unknowable than texts can yet capture and regularize” (xviii). I see a similar difficulty with the human body—our knowledge of it is both greater than and less than that which can be conveyed by risk statistics and lab tests. Just as “without miners’ embodied knowledge texts are incomplete and dangerously misleading,” health decision guides that ignore the experience and values of patients will lead to treatment decisions that at the least leave patients dissatisfied and at the worst damage them physically and mentally. For Sauer, capturing the embodied practice of miners means transcribing gesture and listening to anecdotal knowledge. For writers of health decision guides, serving the readers might mean not only drawing out their anecdotal knowledge but also bringing them to an awareness and validation of their own values in the context of their life situations. Just as Sauer found that miners “have much to contribute to an understanding of the events and decisions that precipitate a disaster,” patients have expert knowledge in their own values and bodies that can help them avoid the disaster of a wrong treatment choice. My tasks in chapters 3 and 4 will be to analyze health decision guides using traditional rhetorical categories and to use feminist standpoint theory to draw out and respect “those marginalized forms of representation that might not be visible with conventional methods of analysis” (Sauer 2003, 6). Sauer calls this the “central methodological problem of feminist theory and

the crux of postmodern cultural studies—to make visible the silent or invisible knowledges that are not present in written texts” (6).

### **Standpoint theory**

Standpoint theory has been a controversial part of several ongoing conversations among feminist scholars for the past 30 years or so. It sprang from the fundamental feminist enterprise of challenging the basis of knowledge and further developing the ideas about the cultural construction of knowledge being explored by Thomas Kuhn, Bruno Latour, Steve Woolgar, and others.<sup>13</sup> Standpoint theory is based on the idea that our beliefs about the world as we know it from our own experience in context can lead to what we take to be truth.

Jaggar says, “A standpoint is a position in society from which certain features of reality come into prominence and from which others are obscured” (2004, 60). Harding and Nancy Hartsock are two of the most prominent voices in this discussion. One thing they agree on is that a standpoint is something much more than simply a perspective or a viewpoint. Harding describes it as a “kind of organic epistemology, methodology, philosophy of science, and social theory that can arise whenever oppressed peoples gain public voice. ‘The social order looks different from the perspective of our lives and our struggles’ they say” (2004, 3).

People who use it as a methodology find that it can explain nature and social relations in otherwise inaccessible ways and that it helps raise consciousness among oppressed people.

This theory can “create oppressed peoples as collective ‘subjects’ [authors] of research rather than only as objects of others’ observations, naming, and management” (3). Feminist writer Chela Sandoval offers, “Any social order which is hierarchically organized into relations of

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<sup>13</sup> See Bruffee (1986) and Kuhn (1970).

dominant and subordinate creates particular subject positions within which the subordinated can legitimately function. These subject positions<sup>14</sup>, once self-consciously recognized by their inhabitants, can become transformed into more effective sites of resistance to the current ordering of power relations” (quoted in Hurtado 140).

Harding says some possible projects in which standpoint theory could be put to use are as follows:

- research about conceptual practices of dominant institutions;
- research from women’s experiences, lives, and activities, not from assumptions and frameworks of institutions (e.g., health, education); and
- research designed by women in science to look beyond sexist ideologies in research disciplines.<sup>15</sup>

(2004, 6)

Use of this theory can also reveal the standpoint of a dominant entity, such as the world of biomedical research and how the political nature of research promotes the interests and concerns of institutions.<sup>16</sup> It can make people more aware that much politically driven research does not reflect women’s and patients’ needs and desires nor, Harding adds, does it give “those who bear the consequences of science and technical decisions . . . a proportionate share in making them” (2000, 256).

Sauer’s feminist analysis of texts of postaccident reports in the mining industry could be said to draw on standpoint theory in that it reveals the marginalizing of voices and the

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<sup>14</sup> What Harding euphemistically calls “resource-producing oppressive situations” (2004, 9)

<sup>15</sup> And perhaps research designed from a patient standpoint to look beyond patient-objectifying practices, the most inhumane resulting in projects such as the experiments conducted in the 1930s at the Tuskegee (Alabama) airbase, in which black enlisted men with syphilis were given a placebo so that doctors could monitor the full course of the disease. (See James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiments*, rev. ed. (New York: Free Press, 1981, 1993).

<sup>16</sup> Which is not necessarily bad—“good politics can produce good science,” standpoint theorists argue.

“rhetorical incompleteness of any single viewpoint” (19), though as already mentioned, a standpoint is much more than a mere viewpoint. One of several others who have seen value in cross-disciplinary applications of standpoint theory is Sandra Harding. She points out three ways people can use standpoint theory: to create an accurate representation of the world, to unpack ideologies of knowledge representatives, and to retool the lessons of oppression into useful critical insights. This last method she calls rearticulation, which can be understood in the sense of respeaking and reconnecting, linking difference in ways that create communities of understanding (12). Shari Stone-Mediatore says this kind of rearticulation can even “challenge members of the dominant culture to rethink their identities” (123).

The role of standpoint theory and feminist epistemology in this paper is to give a space from which to engage the dominant discourse, not to leave the privileged out of the conversation but to question the assumptions that drive the discipline. I am not proposing it as an alternative to science, which is clearly a construct that reflects a social order and social values<sup>17</sup>, but as a way of interacting with and critiquing it. Sandoval points out that standpoint theory is related to the rhetoric of science in that both are concerned with production of knowledge. Because language has a tendency to reproduce certain histories and meanings, “it renders lived experience obscure if it doesn’t fit with dominant language” (Licona). One goal of standpoint theory is to recognize these ordering effects of language and to arrive at a mode of production of knowledge that is egalitarian, not privileged, one that allows competing ideologies into the picture.

For a long time, the rhetoric of science has been driven by Cartesian, modernist notions of a unified theory of knowledge with its underlying assumptions of dichotomous thinking, positivism, and hierarchy. Even after science came to recognize the social

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<sup>17</sup> See Harding (2004), Kuhn (1970), Latour and Woolgar (1986), and Narayan and Harding (2000).

constructedness of its knowledge, biomedical discourse remained steeped in its traditional assumptions and epistemology. In this view humans are “dumb knowers who must struggle to learn the one correct knowledge system” (Harding 2000, 254). This epistemology results in hierarchical binaries such as mind/body, expert/lay, doctor/patient. Gloria Anzuldúa says hierarchy based on expertise leads to the disempowering othering of the subordinate and fosters a condescending attitude, much like colonizers toward colonized: “We need to care for them. We’re invading their country for their own good.” In the biomedical culture, the tendency toward hierarchical relationships leads to doctors who feel that it is incumbent upon them to manipulate the patients. Standpoint theory challenges these assumptions and helps to elevate the subordinate. It acknowledges that none of us are empty vessels awaiting knowledge from some anointed source to set us in motion. Rather we bring to the discussion important information only we know. It fosters epistemological diversity, recognizing us all as smart knowers of imperfect local knowledge systems (only one of which is biomedicine). These smart knowers not only bring their own knowledge, including feelings and experience, but also are capable of “belief sorting” (255). Consider, for example, Harding’s observation about,

the daily health maintenance practices of middle classes in the metropolises. Here individuals commonly use several conflicting knowledge systems. In the United States we use revised vitamin, acupuncture, chiropractic, dietary, exercise, and meditation therapies, not to mention Grandma’s home remedies—which modern biomedicine, until the last few years, claimed were of little or no value. But we also use modern biomedicine. . . . All of us have to be very clever about which knowledge system we use and when; this can be a life-or-death matter. The point is that cognitive diversity is an important scientific value. (254–255)

This viewpoint radically changes how we think about experience in the production of knowledge (Harding 2004, 12; Code 71). Standpoint theory, when overlayed on scientific rhetoric or medical discourse, won't let these discourses simply reinscribe science on readers but rather demands that the diverse standpoints of readers be acknowledged and their local situations be not only respected but valued for the contextualized knowledge they result in.

Just as standpoint theory served the women's movement, which needed knowledge that was for women, and just as it served Sauer's miners who needed their embodied knowledge recognized textually, standpoint theory has been used by health care activists in at least three separate movements during the 1980s and 1990s: the so-called breast cancer wars mentioned in chapter 1, the AIDs movement, and the midwife movement. Each of these activist groups achieved standpoints and recognized that when patients' knowledge-producing capabilities are valued, they have a great deal to contribute to the conversation. Patient groups have voiced their own critical insights about their diseases, conditions, and medical practices and how the biomedical world represents and reacts to and researches them. AIDs activists and breast cancer activists influenced the course of research and to a degree bridged the expert-lay divide.<sup>18 19</sup> And in the past 20 years, midwives have struggled to regain the authority and status usurped by medical doctors when labor and childbirth became medicalized in the 20th century.<sup>20</sup> In each of these cases, the dominant ideology was biomedicine, and each activist group was partially successful in opening the biomedical world to scrutiny, a process Jaggar calls essential to the development of alternatives to the

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<sup>18</sup>See Lerner (2001), Epstein (1998), McCormick, Brown, and Zavestoski (2003), and Braun (2003).

<sup>19</sup>They were not alone in this endeavor. Feminist theorist Ruth Hubbard says, "Ordinary people need to be able to feel pride in the knowledge and experience they accumulate in their daily lives and not always feel overshadowed by so-called experts . . . [and to] help make scientists partners in a democratic enterprise [of scientific inquiry] that's grounded in needs and questions of ordinary people, if science is to be understandable and useful" (217).

<sup>20</sup>See Lay (2000).



hegemonic moral system and vital to the moral ethos of the dominant system too. True foundational values are necessary, she says, because “it would be impossible to develop a system of moral and political ideas unless certain assumptions were temporarily taken for granted,” but if these assumptions aren’t challengeable, “the system based on them becomes a form of dogmatism” (2000, 9). And the dominant ideologies and practices may seem normal and even natural (Harding 2004, 9) so that a not-always-visible pressure to conform to “prevailing interpretation of their unifying assumptions and values” is exerted by the community on its members (Jaggar 2000, 9).

In scientific communities, these shared assumptions are often hidden, even in biomedical texts (8). In fact, Harding says, “The more value-neutral a conceptual framework appears the more likely it is to advance the hegemonous interest of dominant groups, and the less likely it is to be able to detect important actualities of social relations” (2004, 6). In this way the values of the dominant community are reinscribed on new community members and, in the case of health decision guides, on patients. With standpoint theory as one of my tools, I can examine the rhetorical nature of health decision guides and seek ways of creating guides that do more than co-opt patients into the biomedical fold. The starting point is to actually acknowledge the diverse standpoints of biomedicine and patients and recognize and respect their local situations.

Evelyn Fox Keller, in her 1985 work *Reflections on Gender and Science* initiated some of these conversations in the feminist critique of science. In general, like Kuhn, she valued empirical research but saw the need to develop an epistemology that also understood the social construction of knowledge. She was not questioning the value of the scientific pursuit of

reliable, shareable knowledge of the world around us. Indeed scientist's shared commitment to the possibility of reliable knowledge of nature, and to its dependence on experimental replicability and logical coherence, is an indispensable prerequisite for the effectiveness of any scientific venture. What needs to be understood is how these conscious commitments (commitments we can all share) are fueled and elaborated and sometimes also subverted, by the more parochial social, political, and emotional commitments (conscious or not) of particular individuals and groups. (11)

Others in her wake believed standpoint theory could help distinguish "productive from unproductive interests in knowledge" (Harding 2004, 20). Ruth Hubbard, in her book *Profitable Promises* (1995), says it is vital that scientists, despite their firmly held belief that scientific production is not political, "acknowledge the contextual location of their work and its inevitable impact on the political and personal realities of people's lives" (216). For a long time the project of feminists among scientists was a consciousness raising one: Experience in context informs our knowledge. It doesn't matter what your standpoint is. You're going to have one, and it will affect your perceptions, therefore science production cannot help but be political. Such work has led to a general acknowledgment that even medical writing is situated and contingent. When we are aware that knowledge is political, we can be alert to who is validating certain kinds of knowledge and not others. And we can ask, How does what we know determine our attitude toward how we should behave? If scientific knowledge is privileged, deemed the best, most pure knowledge, how does that affect our decision making<sup>21</sup> related to health care treatment?

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<sup>21</sup>Biomedical clinical decision analysis (CDA) reduces decision making to probabilistic judgments and value dichotomy. The problem with CDA is that it uses a prescriptive versus a descriptive approach. (Babrow, Kasch, and Ford 6)

The power of standpoint theory and feminist epistemology is in recognizing local knowledge systems—the most local of course being your own body. Harding’s point is that “cultures have distinctive locations in heterogeneous nature and distinctive interests in those surroundings,” and they use different discursive resources (e.g., “organist, mechanist, or biblical models of nature”) and each discourse “directs scientific attention to different aspects of nature’s regularities and orders them in different causal configurations” (2000, 250). She continues:

Of course, not all local knowledge systems are equally powerful for all projects.

Modern biomedicine is valuable for many purposes; but acupuncture, chiropractic, and vitamin and exercise therapies may be more valuable for some health purposes that modern biomedicine has neglected or misunderstood. Modern philosophy of science’s claims to unique and universal validity obstruct our ability to think our way through such issues. (250)

In light of this, she would agree that it is not useful (she might say dysfunctional) to hold on to universal knowledge claims.<sup>22</sup> And the more important project, Harding says, is how “local knowledges do travel from one culture to another and how elements from different contexts of production are linked and reconstructed in ways that help to produce new knowledge” (253).

### **Approach toward audience**

Using standpoint theory to rethink the interplay of rhetorical elements in the health decision guide genre may lead us to value patients’ embodied knowledge and equalize power between

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<sup>22</sup>See also Lorraine Code on contestable, value-saturated lab science and Ruth Hubbard on the democratization of knowledge and demystification of science. It is not monolithic but dissensual, she says (217).

physicians and patients. Two researchers who have looked at medical discourse through a rhetorical lens are Judy Segal and Mary Specker Stone. Segal researched patient compliance, and Specker Stone wrote about patient agency in diabetes education materials. They both found that “the patient . . . becomes the object of disease and treatment and a subject within the powerful cultural construct of social science” (Specker Stone 204). In this model, as we would expect from a feminist critical perspective, the patient is othered, viewed as everything the physician is not—emotional (vs. rational), inexpert (vs. expert), passive (vs. active).

Segal concludes, because of the unequal doctor-patient relationship related to their knowledge, expert and lay status, and subject positions, “physician and patient do not quite speak the same language; they do not tell the same story of the illness to which they both attend” (94). And the “physician’s effort to impose a technocratic consciousness, to dominate the voice of the life world by the voice of medicine, seriously impairs and distorts essential requirements for mutual dialogue and human interaction” (95). The rest of Segal’s argument explores why patient noncompliance is so persistent a problem and suggests a rhetorical analysis might offer solutions that health communication researchers have failed to consider. Many variables affect compliance, some cultural, some structural, and others rhetorical. It is these rhetorical factors that Segal expands on in her article and that may help to inform this study of health decision guides too. She asks the rhetorical question, Given that the patient-doctor relationship is characterized by distance, objectification of the patient, and an unequal power relationship, is persuasion, that is, patient compliance, likely to occur? Her answer is, of course, no.

She explains by way of Kenneth Burke: “You persuade a man only insofar as you can talk his language by speech, gesture, tonality, order, image, attitude, idea, *identifying* your ways with his. . . . The rhetorician may have to change an audience’s opinion in one respect;

but he can succeed only insofar as he yields to that audience's opinions in other respects. . . . According to this theory of rhetoric, persuasion is a function of familiarity: it is a drama in which the parties are acting together" (96). Segal says the rhetoricians Burke and Perelman suggest that for persuasion to happen, a community must be characterized by a common language, shared values, mutual respect, a willingness to listen and respond to the speaker's viewpoint (96). Without these conditions, the discussion becomes coercive, manipulative. No wonder noncompliance is such a persistent problem. She claims, "Rhetorical theory suggests that noncompliance is an endogenous feature of Western medicine. . . . The biomedical model denies those conditions which are necessary for persuasion to take place" (97). And Specker Stone, in her study of patient agency in the rhetoric of diabetes care, has found that text conventions of biomedical discourse constrain patient agency despite the trend toward increased patient involvement in their care.

This view of rhetorical theory and the patient-doctor relationship suggests that the attempt of health decision guide producers to create guides that facilitate informed choice will likely meet with as little success as patient compliance experts have. Many factors affect decision making, and patient satisfaction with their decisions is tied to the degree of involvement in that process and whether it incorporates human experience (not just biomedical knowledge), values the anecdotal, and uses a "meaning-centered model of care that places the individual, social, and cultural meanings that the patient derives from . . . illness at the center of treatment" (Specker Stone 205).

### **Contemporary audience theory and genres**

One of the most persistent and least helpful conventions of biomedical discourse that might well be remedied by recourse to standpoint theory and contemporary rhetorical audience

theory is the narrowness of the “other” role patients are cast into by the scientific gaze.<sup>23</sup> Part of the blame for this lies in the biomedical genres themselves. One of the primary functions of genre is to construct a relationship between the author and the audience. It cues the audience on its role as passive recipient or active interpreter (Blakeslee 2001, 55). The familiarity of a genre helps the audience know its task (think of the patient history forms presented to you on first doctor’s visit—you give information, the doctor interprets). People who understand genres in the same way are better able to communicate (think of when health decision guides first became common—doctors tended to view them as a challenge to their authority rather than as an opportunity for co-agency, and so such guides sometimes shut down rather than facilitated communication, and I suppose that some still do). Genre theorists are concerned with anything that affects claims and arguments and a writer’s approach to audience, such as the writer’s training, the state of knowledge in a discourse community, and the audience characteristics. Producers of genres used in medical discourse need to tend to these factors too.

The task of approaching your audience is always challenging but perhaps especially confounding when you are faced with a vast, heterogeneous audience, as you are with health decision guides. Two approaches to this rhetorical problem interest me here: one which views the audience as imagined by the author (the audience-invoked model of Walter Ong’s oft-cited 1975 article “The writer’s audience is always a fiction”) and one that tries to address real, known readers, an approach sometimes called audience addressed.

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<sup>23</sup>See McClaren: “The scientific paradigm . . . contributes to the process of domination and objectification of the individual” (164), and so too does the biomedical model.

### **Audience invoked**

With the audience-invoked approach, the author calls on the readers to play an assigned role and cues them in how to do so. Sometimes the mere choice of genre provides this cue (e.g., a reader knows to read a scientific journal article differently than an editorial). The genre does much of the work in establishing the reader-writer relationship. Even so, the author has a great deal of freedom in shaping this relationship, too, not only in choosing how to imagine the audience but also in creating a role for himself or herself, for example, by adopting a charismatic ethos to persuade rather than relying on words alone or by tasking the audience members, calling on or causing them to modify their thinking and behavior. Sometimes two items of the same genre can take different approaches to audience, as Gragson and Selzer point out in their article “Fictionalizing the readers of scholarly articles in biology.” They found, for example, that in one biology article, the author used conventional cues that prompt readers into a highly conventional role, such as a typical evolutionary biologist, by using the pronoun “we,” casting the readers as scientific colleagues, not as inferiors. In another article of the same genre, the author chose to invoke readers as more than just scientific colleagues but also interested in the ethical and humanitarian aspects of the topic under discussion (37).

The audience-invoked approach does have limitations: It minimizes the readers’ role in creating meaning from text and does not fully realize the potential of the interactive nature of the audience-author relationship. It can lead to a stereotypical, uniform conception of audience. Many authors have used this approach successfully, but those who do so unskillfully may risk losing their readers.

### **Audience addressed**

The audience-addressed approach is sometimes called the demographic approach—the author collects data on attitudes, prejudices, habits and knowledge of real readers (Gragson and Selzer 27). With this method, the author attempts to learn specific characteristics of his or her audience, such as what they know and how they know it (Blakeslee 2001, 51) and “adapt[s] discourse to meet its needs” (Ede and Lunsford 160). The audience and author are cooperative negotiators, working with the genre, which is more than mere forms and rules on how to present information for a particular use but, as Bitzer describes it, recurring rhetorical responses to situational exigencies (Berkenkotter and Huckin 5), even phone calls and e-mails—any situated, regularized action. Carol Berkenkotter and Thomas Huckin explain this approach in *Genre Knowledge in Disciplinary Communication*. They view genre as an activity—fluid and responsive to audience needs. In beginning to write, they might ask themselves, Is there anything specific we do as writers to catch the readers’ attention?

### **Audience as partner**

Ann Blakeslee, in her book *Interacting with Audiences*, offers insights into audience and its relationship to the author and the text that illustrate how to blend the previous two approaches to audience into something called the interactive model. This more social approach is based on cooperative interaction between author and audience and depends on developing a long-term and, if possible, face-to-face dialogue that allows the author to target and respond to audience. The medium for this interaction is the text. Before writing, she might ask the potential readers, “Is there anything special you want as a reader that would help you to achieve your goals and make the text fit with your cognitive and physical



abilities?” The final product would be the result of these negotiations with audience. These steps, if used successfully, would place the author somewhere midway between an audience-invoked approach and an audience-addressed approach (50, 66).

The reader is not merely a passive recipient of information, but rather he or she is expected to discern values in relation to that information, to be an active interpreter (55). Andrea Lunsford, in *Reclaiming Rhetorica*, also “is interested in a kind of knowledge that can only be rhetorical, the product of an exchange between speaking subjects. . . . She does not, then, regard either writing or speech as a product representing some prior knowledge, but rather as a process or ‘work in progress,’ that produces both the author and the audience in its text” (311). She argues “meaning is achieved in a collaborative dialogue between the expressive, feeling self and the community’s stable, preserving structure” (266). In traditional rhetorical theory, the author speaks to an audience and seeks action from them, and the role of the audience is to be acted upon. The interactive theory proposed by Blakeslee, Lunsford, and others seeks audience participation and feedback, an approach that gels well with the priorities of standpoint theorists. In chapter 3, I will look at how the creators of a particular health decision guide approached its audience and how the author expects the readers to use the health decision guide. Audience theory can help us recognize that we are co-opting patients into biomedical values, especially when our audience accepts the role we cast them in and holds the same values that underlie our work. And in chapter 4 I will discuss further what the interactive approach might mean in concrete terms for health decision guides that take a patient-centered approach.

### **Weaknesses of a biomedical standpoint**

As mentioned above, guides developed from an exclusively biomedical standpoint result in objectifying patients and dichotomous, nonegalitarian relationships. Closely related to this object/subject split of patient-doctor relationships is the valorization of objectivity itself, which lies in two realities: (1) biomedical discourse is a form of technical communication, which has a strong lingering bent of positivist thought, and (2) biomedicine is a positivist enterprise. These realities have been recognized and critiqued by feminists and those who have offered alternatives to the biomedical model, particularly George Engel, who offered the biopsychosocial model and William Donnelly and Arthur Kleinman, who took Engel's model even further. Engel was a doctor who promoted a model of care that focused on the whole human, not just a diseased part. Donnelly and Kleinman were medical educators who embraced that philosophy and also proposed a humanistic model emphasizing the craft of medicine over the science and saw it as incorporating discourse, history making, classical judgment, and decision making (Specker Stone 204-205). Increasingly, more feminist critiques of science (such as Harding's *The Science Question in Feminism*, Hubbard's *Profitable Promises*, and Lundy Braun's work on breast cancer research) have given us alternative voices and made us aware of the rhetorical nature of the scientific enterprise. Science is not objective. It is situated and contingent—like all rhetoric. Standpoint theory will challenge writers of health decision guides, those who are part of the dominant culture, to rethink their approach toward patients, doctors, and their own role in creating the health decision guides that mediate those social realms. Feminist “contributions can be understood as attempts to envision and participate in democratic, nondogmatic and open-ended dialogues of the sort that are crucial to . . . facilitate more inclusive and egalitarian institutions and practices” (Narayan and Harding ix). Feminist theorist Mary Lay says the

prioritization of rationality is an “elevation which seems almost necessarily to devalue subjectivity and with it feelings, principles, intuition, even one’s sense of self, all of which cannot be objectified and so suffer either neglect or denial by scientists” (quoted in Dombrowski 1994, 126). I suggest that the guide under study, and perhaps the genre as a whole, is hampered by the prejudice of the biomedical community against emotion and by an approach to decision making that is overly reliant on the rational and too little aware of its other rhetorical aspects. That is, it directs the readers to make decisions primarily in terms of logical appeals (logos), largely because it has not used the full range of rhetorical appeals available, particularly appeals to credibility (ethos) and deeply held values (pathos).

### **Balancing appeals to ethos, pathos, logos**

This reliance on rationality has its roots in the rhetorical theory of Aristotle, perhaps even in an interpretation and use of his theory that he would not have agreed with. One of Aristotle’s contributions to rhetoric is his unified theory of persuasion, part of which is a careful categorization of the types of audience one may face: old/young, content/discontent, agitated/calm, and so on. He further categorizes by dividing arguments (proofs) into two primary forms: artistic and inartistic. Inartistic proofs are givens, such as facts. The artistic proofs—creative appeals to logos (words and rationality), pathos (values and emotion), and ethos (credibility)—take into account people in all their complexity (Bizzell and Herzberg 175). Beverly Sauer, in her book *Rhetoric of Risk*, states that Aristotle’s “distinction is fundamental to the notion that evidence alone will not persuade audiences; instead, rhetors must have at their command a range of rhetorical strategies that address the knowledge, understanding, values, belief systems, fears, hope, and shame of the audiences they seek to persuade” (3). People lose their intuition and emotional savvy when they become too

dependent on verbal information for truth. Like Aristotle, who saw value in appeals to the whole person—not just the rational being—feminists acknowledge the value of emotion and reason in arriving at a decision (knowledge). Contrary to the oppositional relationship of traditional epistemology that sets reason and emotion against each other, Alison Jaggar holds that reason versus emotion is not a dichotomy that holds up (1997, 385), rather, these realities are complementary, sometimes the same (394, 395, 399). Jaggar says that even Plato can be an ally of feminists in that he recognized emotions (love) as being at the root of reason (400).

One of Aristotle's most effective strategies is to incorporate into an argument the audience member's own values in such a way that they almost persuade themselves to your view. He called this technique an enthymeme, a powerful means of persuasion when applied appropriately. Some disagreement persists about the definition of enthymeme, but generally it refers to an argument whose first premise is based on an unstated assumption, not a certainty (Bizzell and Herzberg 171). Craig Waddell quotes Bitzer in further defining enthymeme: "It is this participation of the audience in constructing the argument . . . that is the defining characteristic of enthymeme. . . . The power of the enthymeme, then, derives from this: If the audience accepts the premises of the enthymeme, it is drawn into and participates in the construction of the argument; thus, the audience is inclined to persuade itself" (390). The risk in using enthymemes with an unknown audience is that if the audience does not accept your premises, neither will it agree with you (391). In one interpretation of Aristotle's theory, the enthymeme is a subdivision of logos, which because enthymemes are so powerful, implies that Aristotle viewed logos as more valuable too. But in an interpretation offered by William Grimaldi, the artistic proofs are divided into two categories—enthymeme and example, with appeals to logos, ethos, and pathos present in each type (Bizzell and Herzberg 173). This view supports the link between Aristotle and

feminism that I just made wherein emotions and rationality both play a persuasive role, and it undercuts the traditional use of Aristotle “to defend a purely logical or scientific use of language, free from all circumstantial influences” (175). In biomedical discourse, an acknowledgment of that, difficult as it may be, may lead to a more balanced approach toward decision making.

Carolyn Miller and Waddell have analyzed how appeals to ethos, logos, and pathos have been used in various ways in medical rhetoric and risk communication, and they too support a more balanced approach. Waddell, like Miller, is concerned with the role of rhetoric in public policy decisions regarding science, particularly the role of pathos. He states, “The privileged position enjoyed by logos in Western culture has often led to the denial of any appropriate role for pathos in science policy formation” (381). He points out weaknesses of appeals to logos:

- they can be inauthentic and deceptive (a claim he points out was made by Aristotle too);
- they can be tautological, telling us nothing more than the obvious;
- they may lead to agreement but not to conviction; and
- they can lead to morally indefensible conclusions.

(382)

And Sauer echoes these claims in her book on risk and mining: “Overpowering attention to logos renders invisible pathos (appeals to emotions) and ethos (appeals to author’s credibility)” (16). I would add support for this claim from Judy Irwig and her colleagues, who say logos hides dissensus (29), and from Harding, who says it limits critique of the dominant science (2000, 253). I think these lessons have ramifications for health decision guides, too, and in chapters 3 and 4 will discuss them further.

### **Interplay**

Aristotle describes rhetoric as appealing to the whole person through a complex interplay of ethos, logos, and pathos. He never meant for people to use logos at the expense of pathos, nor did he view ethos<sup>24</sup> as what you gain by the skilled use of logos. The most accomplished rhetoricians have a well-developed sense of when to emphasize one form of appeal over another and recognize that at times and for some audiences logos will persuade where ethos fails, and pathos will succeed where ethos is lacking. Miller also sees the three elements as needing one another. An argument fails to persuade when it relies too heavily on logos, as does an argument in which ethos is too closely allied to logos. She says, “An ethos without arete and eunoia provides no basis for agreement on values or for belief in the good intentions of a rhetorical agent” (2004, 207). But the balance is key. Sometimes Miller refers to this interaction as a transformation of one form of appeal into another, “whether it be ethos standing in for expertise or expertise [e.g., logos] standing in for ethos” (204–205). This interactive relationship has been noted by others as well. Waddell refers to their interplay as a symphony (390). His article on pathos in public policy suggests that we balance the overemphasis on logos by considering all three elements as continuously blending and interacting throughout the rhetorical process (383). He argues that a well-considered combination of emotion and logic can lead to appropriate judgment and that, according to Quintilian, appropriateness, not persuasion, is the measure of the ideal orator:

The social construction of appropriateness, however, is not simply a process of noble rhetoric enlightening their audiences, . . . rhetors and audiences together co-create meaning and values through the give-and-take of epistemic rhetoric. Like the ideal

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<sup>24</sup>Which Aristotle sees as made up of good sense (phronesis), goodwill (eunoia), and good moral values (arete) (Kennedy 121).

rhetor, the ideal audience embodies, responds to, and—when the time calls for it—helps to determine the society’s best and most noble sentiments. With the ideal audience, then, an argument is not appropriate because it is persuasive, is persuasive because it is appropriate. (394)

And to be appropriate we need to acknowledge our own standpoint and address our audience’s, both tasks of someone writing from an approach to audience based on the interactive model.

### **Ethos as dwelling place**

The characteristics and power of ethos discussed thus far represent the traditional, discursive views of ethos of Plato, Aristotle, and Quintilian. This type of ethos emphasizes credibility as coming from the rhetor, and in modern texts that apply it, results in an emphasis on design, usability, credibility through discourse, and corporate identity. Miller says the more conventional manifestations of ethos include “institutional affiliation, the explicit framing of methodology, and the display of consensus across multiple experts” and that these traditional elements are important to the granting of credibility from public to experts (2003, 191). One other aspect of ethos that doesn’t quite fit into the discussion above but may prove to be relevant to our discussion of health decision guides is that of “dwelling place.” Michael Hyde, in his book *The Ethos of Rhetoric*, says that this is a meaning of ethos that predates the traditional translation of “moral character” and “ethics.” His book gathers several essays on how discourse can transform space and time into dwelling places where people can communicate and co-create meaning. In Miller’s article in this volume, she says such a place is one “where interlocutors abide, about which they contest, and from which they draw

appeals. Those who dwell within a rhetorical community acquire their character as rhetorical participants from it, as it educates and socializes them” (198). She cautions that an “ethos may metonymize a community that is oppressive, restrictive, secretive, deceptive; its virtues may be ones we would not choose to emulate, even though in many situations we may find ourselves persuaded by them” (199). Again, this is a situation that might well be remedied by heightened awareness of standpoints—not only one’s own, but that of the dominant as well.

### **Methodology**

Finally, let me touch on genre theory briefly because it plays a key role later in the health decision guide exegesis in chapter 3. North American genre theory has done much to expand the role of technical communication, which Miller says, is “shot through with positivist assumptions” (1994, 147). At one time it may have been enough to transmit knowledge, from experts to the public, but technical communication has a much more social and ethical role now. It is more than conveying facts through a conduit unimpeded by fuzzy language.

Miller’s 1989 article “What’s practical about technical writing” explains this idea:

“Practical” doesn’t simply mean useful or handy, but prudent reasoning and is very much related to both ethics and rhetoric (68). In summarizing Miller’s chapter in *Humanistic Aspects of Technical Communication* (1994), Dombrowski says that from this expanded Aristotelian perspective, rhetoric in technical communication is both “highly practical and highly conscious of social responsibility” (22). With this understanding, technical communication becomes a matter of social activity (conduct) rather than of just taking notes from the expert, translating (dumbing down), and writing. It is much more a matter of “arguing in a prudent way toward the good of the community rather than of constructing



texts” (147). The former disenfranchises (Waddell 395), while the expanded notion is a form of interactive communication. As Bazerman puts it, “by using these typified texts we are able to advance our own interests and shape our meanings in relation to complex social systems, and we are able to grant value and consequence to the statements of others” (quoted in Freedman and Medway 79). His later work shows that he pursued a contextual understanding of genre and how these genred activity spaces have much to reveal to us and to the people who live and work in these spaces: “Genre recognition attunes people in deep and complex ways as to what to make of the utterance and what role it plays within human activity”

(quoted in Bazerman, Little, and Chavkin 456). Bazerman says:

Texts mediate human activity at a distance and help enlist and align people to larger social institutions and practices, and text genres provide means of recognizing social relations, obligations, and interactions embodied within communications. Because they can create joint attention and alignment, genres are one of the key mechanisms that people have used to create and to maintain larger forms of social organization. But genres also shape the substantive material that is represented within the bounded space of the text—the meanings, information, and knowledge. . . . A particular genre carries with it the motives and the social relationships implied within that genre.

(456–457)

This understanding of genre is much like that envisioned by Blakeslee and Berkenkotter and Huckin in the concept of interactive audience. Like Bazerman, Berkenkotter and Huckin are interested in communicative acts within a discursive network or system. They characterize the progress in genre analysis as a “communicative turn,” – a “burgeoning interest in intertextual and interdiscursive character of institutional genres” (327). They too explore how

genre systems organize professions and enable them to do their work. Their thesis is that “genres are inherently dynamic rhetorical structures that can be manipulated according to the condition of use, and that genre knowledge is therefore best conceptualized as a form of situated cognition embedded in disciplinary activities” (3).

To carry out their study of genre in academic cultures, they developed what they call the sociocognitive theory of genre. In it they recognize five characteristics of genre: dynamism, situatedness (contextuality), form and content (style of text), duality of structure, and community ownership (4):

**Dynamism.** As stated above in Berkenkotter and Huckin’s thesis statement, genres are “dynamic rhetorical forms.” By dynamic, they mean that genres are responsive to the needs of the people who use them (both the producers and the audience). Even though genres are flexible, they are not overly so—they are stable enough to help give human experience coherence meaning.

**Situatedness.** Simply put, this characteristic reflects that people learn about genres and how to use them by being part of a culture.

**Form and content.** To know a genre is to understand both its form and content. In tending to the form and content of any genre, we must consider audience and situation. This bit of rhetorical advice goes back to the roots of rhetoric. It is our job to know what is appropriate to the topic and to adjust the level of detail accordingly. To that end, the producer of a work of a particular genre needs to know what background knowledge the audience is assumed to have.

**Duality of structure.** Because genres are somewhat flexible, they do not completely constrain our actions, that is, we may adjust them to our needs. This reciprocal relationship

between social structures and genres is termed a duality of structures. That is, “Our use of rhetorical genres is both constitutive of social structure and generative as situated, artful practice” (20). This draws on Giddens’ (1984) work on structuration theory, which accounts for the role of human agency in social structures.

**Community ownership.** Because genres are of use to the whole community, we need to explore how genre “is embedded in the communicative activities of the members of a discipline” and look at the “functions of genre from the perspective of the actor who must draw upon genre knowledge to perform effectively” (2), this could refer to both the producer of the genre and the audience.

In building on her 1995 work with Huckin, Berkenkotter in 2001 added several theoretical assumptions to her sociocognitive theory of genre,<sup>25</sup> two of which I will include here as especially relevant to this project:

- “Genre systems play an intermediate role between institutional structural properties and individual communicative action” (329).
- “One of the central means for identifying texts in a genre system is their intertextual activity. The texts that we see in a genre system are responsive to, refer to, index, or anticipate other texts” (330).

In health decision guides, we will see, the simplistic transmission model doesn’t suffice largely because it further objectifies patients, casting them into that narrow role of nonagency and disempowerment. This study will use North American genre theory to examine how the ideas are “shaped and presented to an audience in a particular form for a

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<sup>25</sup>See Berkenkotter and Huckin, *Genre Knowledge in Disciplinary Communication* (1995), which outlines a sociocognitive theory based on genre as dynamic, situated, community ownership, and duality of structure.

specific purpose” and how genres are “one of the structures of power that institutions wield” (Berkenkotter and Huckin 282–283). We can understand such guides as either constraints or resources and reshape them to meet the needs of the people who use them (Freedman and Medway 71). Berkenkotter and Huckin’s understanding of genres as flexible, “dynamic rhetorical forms” (and by dynamic, they mean that genres are responsive to the needs of the people who use them—both the producers and the audience) is balanced by their relative stability. The power of genres lies in their being flexible yet stable enough to give human experience coherence and meaning (6). That is, “Our use of rhetorical genres is both constitutive of social structure and generative as situated, artful practice” (Freedman and Medway 20).<sup>26</sup>

This idea of genres as stable yet flexible, dynamic, and interactive will blend well with the goal of a patient-centered approach that might benefit from recourse to lessons of feminist epistemology and standpoint theory, even in a guide on prostate cancer, the subject of our genre analysis in chapter 3. One feminist invokes Virginia Woolf in her critique of the privileging of the scientific way of knowing, saying, we need “new viewpoints in order to escape previous constraints.” How can we rethink the communication of risk in early-stage prostate cancer health decision guides from the perspective of those who have the most to lose—their sexual functioning, their continence, and even their lives? Gaining some insight on these questions, and perhaps offering some suggested answers, is the project of the remainder of this thesis. I think a close analysis of this one guide will help us to re-envision the genre as a whole.

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<sup>26</sup>This draws on Giddens’ (1984) work on structuration theory, which accounts for the role of human agency in social structures.

In conclusion, to bring me closer to answers to my primary research questions, outlined in chapter 1, this thesis uses a content study, a close rhetorical analysis of one example of the health decision guide genre. This study's methodology draws on the work of genre theorists Charles Bazerman, Ann Blakeslee, and Carol Berkenkotter and Thomas Huckin. First, I take a closer look at the genre at hand and assesses what I am starting with. I expect this analysis to show that despite all that we know about patients, this guide's content and structure are blinding us to possibilities that it could be serving. As Bazerman suggests, an analysis of the genre's contextual and intertextual features may reveal much about the norms, epistemology, and ideology of its creators: "Writers and readers convey through their textual practices, the beliefs and value systems of the disciplinary cultures in which they participate" (2004, 22). The genre set represents a system of actions and interactions that have specific social locations and functions as well as repeated or recurrent value or function.

Because "specific rhetorical performances are an irreducible mixture of text and context," my analysis will operate between the two extremes of textual and contextual analysis (Bazerman and Little 302). I'll start with the big picture and work down—from context (what's going on around health decision guides) to intertext (what others texts and conversations is this piece of text participating in?) to text (what's happening at the word and sentence level). A contextual rhetorical analysis tries to understand communication in relation to a text's environment, so it needs to be concerned with the setting of production. It needs a "thick description of the rhetorical situation that motivated the item in question." Communication is not self-contained but rather is a "response to other communications (and to other social practices)" (Bazerman 1988, 292).

These contextual elements are what Berkenkotter and Huckin refer to as a genre's situatedness—its communicative chain. This analysis will examine what other conversations this text is participating in. It will show us whether passages in the guide “in fact derive from or speak directly to other discourses and social practices” (Dias et al 297). At a time when the nature of patient-doctor relationships is undergoing transformation, a genre like health decision guides serves a purpose outside just personal decision making. It reveals the shift at the same time it nudges it along to completion, or at least toward its next manifestation. Such guides have “social relevance if not verbal eloquence” (302). This analysis will answer questions of cultural context, the circumstances in which this guide is used, and the rhetorical situation and exigence that it was created in response too—questions of subject, audience, occasion, and purpose. A few years ago, a guide such as this would not have been imaged by patients nor accepted by doctors. The rhetorical conditions are ripe for health decision guides now, it is the kairotic moment for encouraging patient choice and a shift in the balance of power in doctor-patient relationships, for giving patients tools for facilitating their participation in decisions about their health care.

As the analysis in chapter 3 will show, a great deal of stock is put into information, both by patients and doctors. So it is useful to heed Bazerman and Little's cautions, especially since “producing, disseminating, and using information is not as easy as it might appear. Rather than removing deliberations from the realm of values, interests, and social dynamics, information draws discussions into ever more sophisticated and abstracted scenes and systems of rhetorical deliberation and action” (474-475). Our discussion of the context of production and the resulting text will demonstrate this further. Rather than being interested in the sentence-level analysis, I, like Bazerman, will focus more on the interests of discourse

analysis—the relationship between text and context, “features of language and their functions in context” (Bazerman 1988, 60). Rhetorical analysis at this level, “the study of language and the study of how to use it” (280) looks at persuasion in its broadest sense, as the general designs on people’s attitudes, values, action, and beliefs. Rhetorical analysis of this type is “an effort to understand how people within specific social situations attempt to influence others through language” (281). It helps us become aware of the rhetorical tactics and how writers “craft texts to influence people” (8).

Like Gragson and Selzer, I use the rhetorical terms presented in this theoretical overview as an “analytical screen” (283) to enhance my understanding of health decision guides. By examining how the ideas are “shaped and presented to an audience in a particular form for a specific purpose” (282-283) and how genres are “one of the structures of power that institutions wield,” I can, perhaps, understand such guides as either constraints or resources and raise ideas on how to reshape them to meet the needs of the people who use them, particularly patients.

### **Limitations of this study**

Before proceeding with a rhetorical analysis of this health decision guide, let me admit to the limitations of my study. As in Gragson and Selzer’s study of scientific articles, this study addresses contextual and textual features, not with the reception of those features by the audience (42). So although this study may lead us to wonder what effect these guides actually have on patients’ treatment decisions (and the resulting cost effects in the health care system, which is of particular concern to hospitals and insurance companies), it is not an area I intend to address. In fact very little research has been done in this area yet.

Another limitation is that I will not study this genre over time, though genres are made up of “documents that are linked to dynamic and historically evolving discursive practices” (Berkenkotter and Huckin 328), and indeed medicine changes as discursive practices of doctors change, indicating that study over time would be revealing (as Bazerman and others have found). In addition, I will not do a quality review of the genre in general—that has already been done—see Edwards (223-238, 279), Cline (683), and Fagerlin (723-724) and will likely be done again in the future. Many other aspects of decision making, risk communication, and visual rhetoric are related to this discussion (e.g., how to best present data), but owing to a desire to focus on the author’s approach to audience and patient agency, I will leave those as limitations of this study and fodder for the next.



### Chapter 3

#### Analysis

Health decision guides are intended to influence patient decisions related to health treatments. Whether they do so in a way that suits the needs and desires of the biomedical community or in a way that serves the best interests of patients, as determined by patients, is the concern of this chapter. Despite the intention that the guide in this study empower patients in their decision making, I suggest that it, and perhaps the genre as a whole, defines the patient, the patient-doctor relationship, and the patient's decision in such a way as to actually limit patient agency. I argue that its agency-constraining strategies, whether used consciously or not, include an almost exclusively audience-invoked approach, an overemphasis on appeals to rationality, and an underuse of appeals to emotions. These strategies seem to stem from framing the argument totally within the biomedical standpoint, which is rooted in dualistic, hierarchical, positivist thinking. The task in this chapter is to show evidence of these strategies by doing a close rhetorical analysis of a typical health decision guide. I will be critical but not hostile because though I see the shortcomings of such guides, from personal experience with the medical system and from being part of a production team for such guides, I also have respect for their potential for good. I expect this study to reaffirm what many have found to be true—medical writing is situated, contingent, ideological. It may help producers of health decision guides acknowledge the effect of their standpoint, to recognize the standpoints of their readers, and to affirm “the importance of knowing their audience and of the need for a long-term, multifaceted approach to becoming acquainted with their readers” (Zepernick 244).

Decision guides on early-stage prostate cancer are of particular rhetorical interest because of the high degree of uncertainty involved in the treatment choices and outcomes related to this disease. Of all the choices a man at this stage of the disease could make, in most cases none stands out as *the* best option, and all of them have the potential to affect his quality of life and length of life (American Cancer Society n.p., Eng et al. 239). This makes the potential for a health decision guide to influence choices for good or ill that much greater. (Prostate cancer is the most common nonskin cancer in American men. About 230,000 new cases and 30,000 deaths from it are expected this year.) Of the early-stage prostate cancer guides discussed in chapter 2, I have chosen to analyze the one produced by Mayo Clinic because it ranked 10th of 19 in the Fagerlin study and, presumably from its place in the middle of the pack, is neither the worst nor the best, yet clearly has some room for improvement. It is also readily available (including its various permutations during the production process), it reflects current best clinical practices, and the author has established credibility. This guide is situated within Mayo Clinic's general consumer health information web site, *www.MayoClinic.com* (see appendix A for a screen print of the site's home page and appendix B for the first page of the early-stage prostate cancer health decision guide). The site's home page features the following headers across the page, directly below a banner of the corporate triple-shield logo and slogan, "Tools for healthier lives": Diseases and Conditions, Treatment Decisions, Drugs and Supplements, Healthy Living, and Health Tools. The Treatment Decisions section consists of nine health decision guides (one of which is the early-stage prostate cancer decision guide analyzed here). The Health Tools include self-assessments for depression; calculators for body mass index, daily calorie intake, and heart attack risk; quizzes; slide shows; and videos. This early-stage prostate cancer decision guide, which is fairly typical of the genre, contains the following elements, in this order:

introduction, background information on the disease, signs and symptoms, diagnosis and related tests, treatment, and a section titled “Things to Consider,” which is a catchall question-and-answer section for points not covered in the main text. It also includes genres within the genre: patient case studies, an interview with a doctor, medical illustrations, and videos. In this analysis, I will focus on the introduction and those sections that are most directly related to treatment decisions—the treatment section, the doctor interview, and the patient stories.

### **Strategy 1: Approach to audience**

Of the three approaches to audience discussed in chapter 2, this guide primarily relies on the reader-invoked mode.

#### **Reader invoked**

An author of a health decision guide might imagine his or her readers to be conventional, receptive, obedient patients who unquestioningly take their doctor’s advice, or as empowered, inquisitive, and intent on making their own informed health decisions. Or something in between. These choices depend on the author’s perspective, motives, and goals. What does he or she want the writing to do? So in examining how the reader is imagined, I will likely learn something about the author as well.

This guide begins with a section titled “Welcome,” which invites the reader into the author’s world, biomedicine. The first sentence invokes a reader who is a distraught patient—the helpless recipient of bad news: “Receiving a diagnosis of prostate cancer can be scary.” The second sentence puts the disease in the subject position: “It can lead you to fear, panic, and hurried decisions.” The invoked reader is in need of calm answers, offered here by

the author, who assumes the stance of rational physician: “There’s no need to rush.” The authorial voice throughout is much like that which Miller found in her nuclear report’s executive summary: “a highly knowledgeable but empathetic expert who speaks authoritatively but with reassurance, repetition, and apparent understanding of the audience’s concern” (2003, 192). The next paragraph cues the reader to assume a more controlled attitude. He is urged to gather information, learn, talk with others, seek opinions. All of this is in the imperative mood—directions from the author to the reader. These cues prompt the reader into a “highly conventional role” (Gragson and Selzer 30), that of a patient in a biomedical discourse community. The reader seems to be imagined as a sort of doctor-in-training. All other roles—father, spouse, businessman, community leader—recede. Rather, he is directed to be like physicians—objective, rational, fair “reasonable pursuers of factual truth” (32). The reader is presumed to be, if not schooled in the ethos of science (32), at least receptive to it. But the reader is also cast in the traditionally patientlike role of respectful inferiority, taking “notes from the master in front” (33). What the author is directing the reader to do is no small task. The author presumes the reader to be highly motivated, interested in his research project, and committed to the decision-making process. The reader is told to expect to take at least an hour to read through the guide. These assumptions about the reader are demonstrated again later in the guide where prostate specific antigen (PSA) testing, a complex and controversial subject, is discussed: “In deciding whether you should have a PSA test, learn about PSA testing, evaluate its benefits and limitations in your case, and talk with your doctor.” That’s a steep order—some doctors even struggle with determining the benefits and limits of PSA testing (see Liberatore et al. and Gretzer and Partin). The author seems to be expressing confidence in the reader to do these tasks. It assumes the reader has the motivation, support, and ability to use the guide effectively.

The reader invoked by the author is first a frightened man who has been diagnosed with prostate cancer and second an inductee into the biomedical world who will overcome his fears by seeking knowledge and using reason and has the education to do so. The stated goals for the reader are “heightened understanding” and “more balanced understanding.” The relationship between the author and reader is hierarchical—a listen-and-learn mode<sup>27</sup> reinforced by overuse of the word *important*, as in, “It is extremely important to understand,” which implies in a sort of condescending way that the reader cannot discern for himself what is important. This rational-man reader role is carried over into the next section, “About Prostate Cancer,” which has a textbooklike approach. It gives straightforward biological background information on the prostate gland and the disease. This section uses primarily unqualified indicative sentences.

A shift in mood begins with the section titled “Treatment Options.” Here the implied reader changes from information seeker and consumer to information processor. The language becomes much more ambiguous, with hedges and qualifiers. The author becomes less authoritative-sounding by using softer terms, such as “may,” “perhaps,” and “consider,” by addressing the reader as “you,” by using an informal style (contractions, lay terms), and by avoiding imperative sentences that directly tell the reader what to do. That is, rather than saying “See your doctor,” “Talk with your doctor,” “Walk as soon as you can,” the author phrases such instructions to the reader as suggestions, for example: “It’s recommended that you try to walk . . .” This approach shifts the implied reader’s role to one of more agency but one still largely constrained by the doctor, the cancer, and the drugs, all of which act on the reader: “The drugs are resumed,” “The seeds are injected,” “The surgeon makes a cut.” And the patient is most often referred to in relation to the parts being treated, reflecting

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<sup>27</sup> See Slack, Miller, and Doak (1993) for more on this transmission mode of communication.

biomedicine's emphasis on disease over person and its inherent mind/body split (even the opening page of the guide displays a big, red, disembodied prostate gland [see appendix B]).

In the treatment section, the author uses style to match the scientific objectivity he or she represents. Scientific writing has long been tied to concise style. Here use of it not only casts the author in a particular light but also fleshes out the imagined role of the audience: "The use of brevity . . . gives the impression of control, as if the authors were very carefully and consciously reporting only the most crucial portion of their work. We, as readers, are therefore treated as if we deserved to see only the best, most privileged information; we are given the author's full confidence" (Montgomery 18).

Slightly different audiences are imagined by the very different authors in each of the next two sections, "Meet the Mayo Doctor," which is an interview with a urologist discussing various treatment approaches, and "Personal Stories," which is a collection of interviews with five patients, each of whom chose a different method of treatment.

**Patient as "other."** In the "Meet the Mayo Doctor" section, the author's position is one of authority, and the reader is approached as impersonal other—the object of investigation. In fact, responses to the interviewer's questions are addressed to the anonymous questioner, not to an imagined patient. The style of this section is more formal: the doctor refers to the reader as "one" rather than "you," uses more undefined jargon (e.g., definitive therapy, comorbidity), and relies primarily on the imperative mood—giving the section a directorial flavor. In addition, agency is presumed to lie more heavily with the doctor. The first references to decision making and information gathering are as activities of the doctors: "We gauge . . ." "We deal with . . ." "We can select . . ." and "We can use our best estimate. . . ." In each of these instances, *we* refers to the doctor and his colleagues, not

to the doctor and his patient. There is very little sense of patient-doctor co-agency, though the doctor does acknowledge that once he has shared his knowledge (again, the transmission mode from expert to lay is evident), the decision is the patient's. This tone reinforces the divide between expert and lay.

**Patient as author-compatriot.** In the personal stories of five men who have undergone treatment for early-stage prostate cancer, the patients are the authorial voice. They assume the stance of knowledgeable guide with valuable information and imagine the audience to be people quite like them when they were at the beginning of their cancer experience—vulnerable knowledge-seekers. These stories have a more personal tone than the doctor section, avoiding jargon and referring to the reader as “you.” In each one the man views himself as the primary decision maker, but in all the stories the men slip into a passive role when they talk about receiving the diagnosis (“The biopsy revealed, . . .” “The diagnosis came, . . .” “A screening test uncovered . . .”), perhaps reflecting the sense of helplessness people feel when cancer makes itself known. Even the doctor disappears in these sentences—the powerful actor is the technology, the tests, the bad news. The diagnosis, the disease, and the treatment all act on the men. In the face of that, they each took control of what they could—their treatment decisions, their values, their relationships with their doctors. The main theme running through these stories is, Find out more, educate yourself. The subject-verb-noun phrases in which patients are active are related to information gathering: “I did research, . . .” “read books, . . .” “attended meetings, . . .” “spoke with doctors” . . . “weighed pros and cons.” These personal stories reflect the sense of agency that these men feel in relation to their own health. After shaking off the victim mode sensed in statements about being diagnosed, the men adopt the authorial role of advice-giver.

In summary, the reader invoked in this guide changes depending on the stance of the author. In the treatment and doctor sections, the implied reader is an everyman—a blank-slated layman whose attitudes toward illness and health care are being shaped by the guide to mirror those of his doctor and the biomedical model of health care. In the patient stories, the implied reader is someone just like the author—a man working through the reality of cancer and the decision-making process with the help of his friends, family, and doctors.

### **Reader addressed**

The reader addressed approach to audience might be termed “the demographic approach,” which is concerned with usability and design geared toward a known audience based on available data—derived from previous research and responses to surveys about the web site. Understanding the interests of your audience, though emphasized in business communication and other fields, is rarely tended to in public health information, which does very little to acknowledge the background, interests, and needs of nonscientific audiences (Nelson et al. 8). Even though we know much about the readers of health decision guides, little about this guide indicates that it was tailored to them. It lacks a sense of being fluid and responsive to audience needs, two characteristics of the audience-addressed approach noted by Berkenkotter and Huckin (4). This guide is revised on a regular basis and does contain a survey for reader feedback, which implies the information gathered may affect its production. But so far it does not seem to acknowledge concrete characteristics of the readers’ individuality. Data is not broken down by race, age, disease stage (though the personal stories do reflect a wide age range). Nor are the readers’ varied starting points—emotionally, intellectually, and physically—addressed. In addition, the guide does not thoroughly discuss



costs, access, quality, and choice and how they might affect one another in the context of a patient's own life circumstances. In the treatment section and "Meet the Mayo Doctor" section, there seems to be no understanding of the reader in a context other than patient in exam room seeking doctor's help, skill, and knowledge. It gives no indication that the author has gained a sense of patients' overlapping communities, their multiple standpoints. Producers of a guide that successfully addresses its readers might do well to heed Mirel and Spilka's idea that "the notion of context is critical. . . . We must understand the physical, social, and cultural contexts in which users live and work" (xii).

### **Reader as interactive**

As mentioned in chapter 2, Blakeslee describes the reader-as-interactive approach as a social, cooperative interaction between author and audience. In evaluating whether this guide uses this approach, I would need to see signs that the reader is not viewed as merely a passive recipient of information but rather is expected to discern values in relation to that information—he is an active interpreter (Blakeslee 55). Little evidence of this exists in the guide, and the questions that are included that may actually guide him are tagged onto the end in a section called "Things to Consider." Nothing shows me that readers are invited to not only read, question, and seek more input but also to engage in creating their own meaning and in turn affect how the guide itself is produced. In another of Berkenkotter and Huckin's requirements for sociocognitive genred interactivity, the text must reflect other texts. This text does so by drawing on a network of medical genres (such as Mayo practice guidelines, medical literature, doctor e-mails, treatment plans, test results, patient histories) and presuming the audience is aware of the ongoing biomedical discussions that it is drawing on and contributing to. Such discussions include the informed choice debate and evidence-based

medicine movement and the prostate-specific antigen testing controversy. It even hints at the ongoing tension between proponents of the biomedical model and the biopsychosocial model and other alternative approaches. Passages in the guide draw from other discourses and the social practices of doctors and the biomedical world, and like the documents Specker Stone analyzed in her study of health communications, the guide “selectively reflects certain aspects of reality while deflecting other aspects” (212). But when we ask, as Jaggar urges us to do, whose interests are reflected by these incorporated discussions and intertextual references, whose “beliefs, power relations, and assumptions of the community” are reflected (Dias et al. 188), it is clear that they are from biomedical genres. A closer look at such intertextual elements reveals not only a biomedical stance but also an apparent bias toward active treatment over watchful waiting and a bias toward a particular treatment—a surgical procedure called radical prostatectomy (the most frequently used and traditional method of treating early-stage prostate cancer).<sup>28</sup>

### **Critique of strategy 1 (approach to audience)**

This guide’s almost exclusively audience-invoked approach is a disservice to the readers. By casting the implied readers as “dumb knowers” (Harding 2000, 254), respectfully inferior co-scientists who are expected to read this guide, take their questions to the doctor, and listen to his or her answers, they are drafted into the biomedical world. In addition, they are cast primarily in a listening mode. The weaknesses of this sender-receiver mode of communication are apparent.<sup>29</sup> Its exacerbation of the expert-lay divide does little to

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<sup>28</sup>The surgery section contains 53 cites and three references to studies, the most definitive language (e.g., the “cancer is completely removed”), and the most detailed description of procedure itself. This is the longest section and is the only treatment section with medical illustrations.

<sup>29</sup>See Slack, Miller, and Doak.

engender trust in the readers.<sup>30</sup> I think the reader-implied model used in this guide tends to manipulate the reader—guiding judgment (toward action), controlling reaction (e.g., by setting elements related to decision making in pro and con columns rather than letting the reader determine which effect is a pro and which a con in his personal context), by limiting evaluability of elements (by giving equal weight to items of disparate importance in pro-con charts, by not using direct comparative charts, and, particularly, by comparing noncomparable groups).

Signs that the reader-addressed approach was attempted are evident in the use of patient stories—they may help the readers identify with the text and get a sense that their concerns have been taken into account, but the men in the case studies all seem accepting of the limited role patients are given in the biomedical world, and they each adopt a similar decision-making approach. The patient stories represent a wide age range, but little else might foster identification with a diverse readership.

### **Strategy 2: Use of artistic proofs (logos, pathos, and ethos)**

In light of the author's stance toward audience in this guide, I suggest that it does not effectively use the artistic proofs, that is, arguments from ethos, pathos, and logos, to communicate risk about various treatments for early-stage prostate cancer and to guide decision making. It overemphasizes appeals to rationality (logos) at the expense of appeals to credibility (ethos) and emotions (pathos). It presumes that when you have evidence-based medicine research and its attendant statistics and probabilities, it only makes sense to do what the numbers suggest. It devalues feelings and experience and overemphasizes the "efficacy of reasonable and scientifically informed behavior" (Segal 92). The bias toward these

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<sup>30</sup> See Cooter and Pumfrey (1994).

biomedical discursive practices constrain patient agency by minimizing the place of lay knowledge in the decision-making matrix. This guide reflects the biomedical model, which is the dominant approach to medical care in Western society, and the dominant by nature excludes those who think differently or do not share its assumptions (Jaggar 3).

So far in this text I have seen the reader envisioned as a highly emotional blank-slated layman patient and as doctor-in-training in pursuit of truth, with varying degrees of agency assigned to or embraced by him. Because the rational pursuer of truth role is predominant, it follows that the persuasive appeals used in this guide would be heavily reliant on logos. Even a cursory look at the guide's treatment sections shows a preference for logos: Information is the answer—it will lead you to your goal, that is, a definitive treatment decision. Let's see if that observation holds up under closer scrutiny.

### **Logos**

The guide's textbookish format is dominated by medical illustrations, lists of symptoms, charts listing the pros and cons of each treatment option, statistics, a glossary, and a list of links to related articles on the Mayo Clinic web site and other information sites beyond the clinic (of these web links, only one refers to psychological or social resources). The treatment section uses more than 150 citations to medical literature (again, only one of which points to a psychological or social resource, the rest are biomedical).<sup>31</sup> Sentences in the indicative mood predominate, and from the welcome page onward, the author emphasizes the importance of gathering information rather than discerning feelings or appealing to the emotions or establishing the credibility of the author and clinic. The word *information* is used five times on page 1 alone. The "Meet the Doctor" section begins with gathering more

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<sup>31</sup>All citations are removed from the guide before it is loaded onto the web site for public viewing.

information, primarily biomedical data—patient’s health status, expected longevity, tumor size, tumor spread. Nothing is mentioned of learning more about the patient’s context—his social and family situation or his emotional status and value system. The decision-making process is driven by logos—the attitude is that with enough information, you will arrive at the right choice. The doctor reflects this classic biomedical approach when he says, “I think that treatment decisions and timing of those decisions can be driven primarily by the tumor factors.” The reliance on logos is a theme throughout the section that features personal stories of patients with prostate cancer. Each patient sets out on a fact-finding mission in response to his diagnosis. Patients turn to the Internet, books, self-education, doctors, medical literature, and other men with the disease. One said he became an information junkie, and another said that he felt as if he was involved in “an incredible process of exploration and aggressive information gathering.” My hunch that logos is the preferred mode of appeal in this persuasive and informative guide seems justified. But before drawing conclusions and critiquing the author’s approach, let’s also look at how ethos and pathos are used.<sup>32</sup>

### **Ethos**

Despite this clear textual emphasis on logos, much about the guide relies on appeals to ethos, particularly at the beginning and end, the traditional placement for such elements. In fact, the banner at the top of each page is a sort of combination of ethos and logos. It features the Mayo Clinic triple-shield logo and the slogan, “Tools for healthier lives.”<sup>33</sup> This banner

<sup>32</sup>It might also be interesting in a future study to look at a guide for women, such as Mayo’s adjuvant therapy for breast cancer guide, to see whether there is a similarly heavy reliance on logos, or whether a guide for men is intentionally masculinized with the traditionally rational approach.

<sup>33</sup>The web site’s banner when the site launched in 2000 was a strip of dreamy-looking cirrus clouds in blue sky and the slogan “Reliable Information for a Healthier Life,” and then it evolved into a plain horizontal banner with Mayo Clinic’s triple-shield logo, a stethoscope, and the slogan “Reliable Tools for a Healthier Life,” and now the stethoscope has been removed and only the triple-shield logo with the slogan “Tools for Healthier Lives” is used.

not only reflects appeals to both logos and ethos but also identifies which of the two different kinds of ethos discussed in chapter 2—discursive and nondiscursive—Mayo Clinic relies on, that is, the discursive form. Discursive ethos, from a traditional rhetorical perspective, is authority without providing logical proof of it. An author’s “ethos is comprised of the author’s ethical and intellectual stance toward the subject” (Couture and Kent 94). Web sites that want to project this kind of authority pay attention to elements such as a strong corporate identity, usability, and design. For example, the web site’s overall look, reliance on the Mayo Clinic logo and reputation, and the inherent ethos of science (science as standing in for ethos [Miller 2003, 189]) serve to enhance discursive ethos. The fact that doctors themselves are imbued with that scientific ethos is reflected in the inclusion of the section “Meet the Mayo Doctor,” which is the first section following the treatment section. Even the title of the section implies it is a privilege to “meet” the specialist, though it is just a taped interview. Other ethos-building rhetorical moves in this discursive sense are frequent references to science, studies, and doctors, the placement of the Mayo Clinic byline on every page, and the inclusion of negatives; for example, on page 1 of the guide, Mayo forthrightly admits that doctors tend to be biased toward their own specialty. But by admitting this and inviting readers into the decision-making process, this negative is turned into an opportunity for partnership, for building Mayo’s ethos, and, conveniently, for making a case for the usefulness of the guide (if your doctor’s ethos is doubtful, you will need to gather information, which is why you should stay and read this guide). This sort of ethos combines an appeal to logos—logos is the power to deal with biased doctors. Here’s another example of Mayo’s willingness to include the negative, and thus build credibility: In one of the personal stories, the patient is quoted as saying, “The surgeon . . . he wants to cut.” The editors could have removed that statement. But leaving it in, sharing the biases of doctors

themselves, is a trust-building maneuver. In another story, a patient said with surgery he would risk “total incontinence,” which is an overstatement, as one doctor-editor pointed out during the revision process. Another patient said that radiation therapy would result in no sexual dysfunction and incontinence—also a misstatement. But again Mayo editors allowed the comments to stand—to let patients speak in their own voices. Like these men, the readers will have to learn to sort good information from bad. By leaving in the patients’ own words, the editors may potentially be increasing the ethos of the site, particularly in the sense of patients identifying with it.<sup>34</sup>

Another technique used to increase the ethos of the site and reinforce the role of author as trusted doctor-adviser is to present the patient-doctor relationship in a favorable light. Phrases like the following are used liberally throughout the personal stories section: “Doctors worked with me”; “The two of them work together in managing Jackson’s condition”; “I had confidence in my doctor—his recommendations didn’t conflict with knowledge I gathered elsewhere.” One of the most oft-repeated phrases throughout the guide is, “Talk with your doctor,” further building trust in doctors and drawing the reader into the biomedical fold.

Eunoia, the good will aspect of ethos, is reflected in the author’s avoiding imperatives (which can seem bossy) and a condescending tone (e.g., a guideline for all Mayo Clinic health information products is to avoid the word *should*, as in “you should talk with your doctor” or “you should have a PSA test every year”). Two weaknesses in this area are avoiding an arrogant stance (see the previous comments on “Meet the Mayo Clinic Doctor”) and not making presumptions about the audience (see the discussion above about the

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<sup>34</sup>This is something like the philosophy of the web site Wikipedia ([www.wikipedia.com](http://www.wikipedia.com)), which allows anyone to type in an entry, and anyone else to come in and correct any entry, thus fostering a sense of ownership and building a community of knowledge-makers.

audience-invoked approach). Mayo's not including on its web site (or in its printed books) medical literature citations and an overall bibliography is based on its ethos—authority without providing logical proof of it. But not including this information might be perceived as presumptuous in that it assumes readers would not be interested in source information. But overall, the mere fact of offering a health decision guide and encouraging readers to be involved and empowered is an act of good will on the part of Mayo Clinic.

Nondiscursive forms of ethos are reflected on the welcome page, the purpose of which is to establish good will, get the reader's attention, and make him feel welcome. Here the key word is *identification* rather than *identity*. This form of ethos draws not so much on Mayo Clinic's corporate identity as on the site's ability to get readers to recognize themselves and their needs and values somewhere on the site and to get them to stay and visit awhile. First-person accounts are capable of doing this because they "open the door to others' common experience" (Couture and Kent 99). Such stories are included "for reasons of ethos or pathos or for Burkean identification" (151). The stories used in this guide are an example of an attempt to foster the community ownership Berkenkotter and Huckin speak of as a vital element of a genre (8). One of the keys to identification is diversity—this is partly accomplished on the opening page by showcasing the mug shots of five men who have had cancer and linking to their stories.<sup>35</sup> Ethos garnered from nondiscursive means such as these helps the readers "consider another person's experience and recognize them as our own" (Borchers 19). The men profiled in the patient stories project this type of ethos. It derives not only from their physical and emotional experience of disease and patienthood but also from the readers' trusting that their motivation in self-disclosure is to help others. Personal stories

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<sup>35</sup> An unfortunate design flaw related to these mug shots is that the two columns of four stacked boxes each sort of call to mind the stacked tombs of a mausoleum. And, to me, the three blacked out squares (see appendix B) seem to represent those who have died from prostate cancer, which is probably not the designer's intent.



serve to increase ethos in both discursive (traditional) and nondiscursive senses. Self-disclosure is an ethos-constructing strategy used from long before Aristotle's day. By situating the knowledge and "making present the writers' subjectivity and situation in order to contextualize her or his interpretation" (Couture and Kent 146), both forms of ethos are heightened. This display of self has an epideictic function as well, the men's praise and blame of their doctors and the treatment decisions (in these cases, it is all praise). In addition, the audience is presupposed in these stories, too; that is, "the self-presentations are geared toward the envisioned audience" (146), which is made up of male patients with early-stage prostate cancer on a fact-finding mission. This section of faces-of-prostate-cancer testimonials begins to create a sense of community of like-situated men. The problem here is that even though each treatment option is represented by a different man, the men are all quite similar in their outlooks toward disease and health care and their decision-making process. They seem to have been co-opted into the world of biomedicine, adopting the narrow role typically offered patients. They are each satisfied with their decisions and outcomes, and they each used a very simple "gather information and decide with doctor" approach. This will make it difficult for men who don't hold these viewpoints and attitudes to identify with this web site.

### **Pathos**

Appeals to pathos are persuasive reasons from deeply held values, not merely superficial appeals to emotions.<sup>36</sup> Ironically, it would seem that one of the most deeply held, presumed values of this guide is that emotions are somehow deficient, to be mastered by reason. Emotions are not your ally in discerning the best choice for you. It expresses this

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<sup>36</sup>See Waddell 390-391.

value by mentioning only negative emotions and steering readers toward the more reliable, reasonable logos. Beginning with the welcome section, emotions are viewed as suspect, something that will rush you toward premature judgment. The detrimental effects of fear and anxiety are to be avoided by listening to the calming voice of the doctor (the implied author) and by searching out knowledge. Information is the means to emotional control.<sup>37</sup> Each man expressed a sense of powerlessness, being disabled by his feelings. The men all remedied their fear and uncertainty by turning to information. Nowhere does the guide suggest recourse to emotions as a valuable part of the decision-making process.

This marginalization of the emotional aspects of decision making is evident in other ways. When the reader is referred by the guide to a doctor, he is being directed to the specialists in urology and radiology, not a counselor. Emotions and values, mentioned once in the introductory material, are not mentioned again until the “Things to Consider” section at the end of the guide—a sort of catchall question-and-answer section for items not integrated into the main text. It includes such things as how treatment will affect your lifestyle and your relationship with your life partner, and how much you are likely to worry about recurrence after treatment, all of which could be seen as related to the emotional aspects of the decision. Their placement at the end bespeaks their devalued status in the biomedical world.

Pathos, in the sense of appeals to deeply held values, is used throughout this guide, but the values assumed to be shared by the audiences are generally biomedical values—belief in the reliance on data, curing, treating, and acting. A few of the other underlying values expressed throughout are that once you have been diagnosed with cancer, you cannot have

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<sup>37</sup>In an electronic search of the document, “think” is used 56 times (mostly in the doctor interview), and “feel” is used 23 times.

both quantity *and* quality of life; it is best to cure at all cost; it is not wise to trust the anecdotal; and technological advancement is inherently good. Basing communication on such underlying values is a powerful rhetorical tool because of their near invisibility. Harding's statement (see chapter 2) about apparent value neutrality of some conceptual frameworks relates to the underlying biomedical framework of this guide and also seems an apt description of this power of assumed values.

### **Critique of strategy 2 (use of artistic proofs)**

So overall, the approach this guide takes, to borrow Miller's assessment of the nuclear report in her 2003 study, is a "traditionally impartial or objective scientific ethos with a paternalistic authority" (193). It assumes the audience would be most receptive to arguments from logos, which in the medical arena means data, statistics, evidence-based literature, and holds a generally suspect view of the emotional and anecdotal. It stresses the technical knowledge of evidence-based studies, "the expertise that authorizes its claims" (193). This "overpowering attention to logos renders invisible pathos, the role of emotions" (Sauer 2003, 16).

I do, however, see some interplay between these elements in this guide—at times logos stands in for ethos. For example, logos is turned into ethos by frequent references to the doctor's reliance on technology: "precise mapping," "custom-designed shields," "technological advances." And just as fear can become immobilizing, so too can an overwhelming amount of data and statistics. In such a case, pathos may well achieve what logos cannot—an emotionally intelligent decision. An overemphasis on logos reduces decision making to a simple dichotomy—right or wrong, good or bad—a mere matter of toting up the pros and cons. I will suggest in chapter 4 that the guide needs to use more of

this interplay. Rather than relegating the psychological, emotional, and social considerations to brief treatment at the end of the guide, they need to be integrated throughout the guide as a vital element of the decision-making process.

The reason Mayo's version of this strategy might be considered a deficiency are many, especially from a feminist standpoint, as I will discuss further in chapter 4. But perhaps the most important, because it gives a motivation to change, is that, as noted in chapter 1, if the audience does not accept your premise (these underlying values), the argument will collapse. Health decision guides will fail if a reader is irritated by assumptions made by the author. The reader will simply move on to another resource.

### **Strategy 3: Representing just one standpoint**

This guide represents just one standpoint—the biomedical. It is certainly the prerogative of an author to write from his or her own standpoint, but doing so in health decision guides has the potential of alienating the very people you are trying to reach. By leaving out or not acknowledging patients' knowledges, attitudes, values, and experience, the guide might be more suitably termed an indoctrinator than a guide. Even when the five patients tell their stories, they are seemingly doing so as members of the biomedical community, perhaps unaware of their "othered" status and their willingness to parrot biomedical values. The problem with presenting just one standpoint is that it reinforces the doctor as dominant and the patient as subordinate. As Margaret McClaren states, "Subordination is enforced through the representation of woman as inferior . . . in medical discourse" (163). Substitute *patient* for *woman* in this quote, and it captures the same problem of hierarchy in this guide.

Doctors are "likely to feel their authority threatened by dissenters" (Jaggar 9), by those who would demand that patients have a standpoint other than "other," the object of

doctors' study, that they have standing as collective patients, equal to and making demands of doctors. But by representing just the biomedical standpoint, this guide is missing an opportunity to facilitate a shift in patient-doctor relationships to one of productive, respectful co-agency and to help patients to recognize their own embodied knowledge and truly guide them in a discernment process that leads to a decision that they can be satisfied with.

### **Conclusion**

The evidence thus far would indicate that this health decision guide constructs a biomedical narrative not a patient-centered narrative. If the guide's goal was to inform, it did that. If it was to guide someone through the decision-making process, it failed. If it was to objectify and condescend, it did that. But I don't think that was its intention. It was, rather, an unavoidable result of being produced from a particular standpoint. By calling attention to the strategies used in this guide, I hope to show producers of health decision guides the value in re-envisioning them and recognizing their standpoint and the consequences of their rhetorical choices. In addition, by showing the users of health care guides the weaknesses of the traditional discursive techniques employed, I hope that they might become more selective in the guides they choose to use and more demanding of what the health information world produces.

## **Chapter 4**

### **Recommendations**

Applying the insights from rhetorical and feminist theories in this analysis of a health decision guide has, I think, brought me closer to answering my three primary research questions. It has shown me that the author's approach to audience (1) could benefit from being more interactive, (2) would be more effective with an increased balance of arguments from ethos, pathos, and logos, and (3), perhaps most important to a re-envisioning of such guides, needs to take a more patient-centered approach by acknowledging the patient's knowledges, attitudes, and standpoints. Making these changes may lead to guides that develop patients' voices and use language that can be shared by two worlds—the doctors' biomedical world and the patients' life world. I think that if the authors shift their worldview or temporarily adopt, for the sake of a better product, a different standpoint, they would facilitate empowered patient agency. This chapter will present recommendations for a re-envisioning of health decision guides based on the preceding literature review in chapter 2 and the genre analysis in chapter 3. The concerns of this chapter are divided into two broad categories—the theoretical and the practical. The theoretical section will show the possibilities in adopting a patient-centered viewpoint and the ramifications of standpoint theory, with its emphasis on context and the local situation—primarily a philosophical shift from a guide that is seemingly based on social contract theory to one that also reflects an ethic of care. The practical section will make specific recommendations on how to adjust the approach to audience and make guides more balanced in their appeals to rationality, emotions, and credibility (though this balance will also be significantly affected by the philosophical shift that incorporates an ethic of care too).

### **A new theory for health decision guides**

The ramifications of the shifting patient-doctor dynamic and the adoption of a patient-centered viewpoint open up interesting possibilities for health decision guides. Based on the analysis in chapter 3, it is clear that this guide, and perhaps the genre in general, reflects much about the norms, epistemology, and ideology of its creators, as you would expect from any genre. The writers have conveyed through their textual practices, “the beliefs and value systems of the disciplinary cultures in which they participate” (Freedman and Medway 22). In this case, the predominant culture is biomedicine and traditional, positivist medical discourse. The values of this system were touched on briefly in chapters 2 and 3—they are primarily curing, treating<sup>38</sup>, relieving pain, and researching. The biomedical value system tends to neglect the knowledge of personal experience (the psychological, social, and emotional) in favor of the empirical (lab tests, physical exams, and evidence-based medical literature). This epistemological positivism is valorized, yet it is also limiting.<sup>39</sup> I suggest that overemphasis on these characteristics to the exclusion of others weakens the potential of this genre to facilitate patient agency. And I also suggest that because these traditional biomedical traits are all symptomatic of the traditional social contract ethic<sup>40</sup> that structures the patient-doctor relationship, they are something that we can remedy with a basic philosophical shift. Feminists have argued that an ethic based on social contract theory, because it “defines moral justification in terms of universal consensus in conditions of domination-free communication” (Jaggar 2), is inadequate for the complexities of our moral and political

<sup>38</sup>See Mary Lay’s *Body Talk: Rhetoric, Technology, Reproduction* (Madison, WI: University of Wisconsin Press, 2000) for a critique of biomedicine’s view on the unacceptability of nonintervention (32, 33).

<sup>39</sup>See Fox Keller (178), Jaggar (399), and Bruffee for critiques of positivism.

<sup>40</sup>Social contract theory is a long-standing view expressed since ancient times, and revisited by various philosophers since that the moral and political duties of people are dependent upon a spoken or implied agreement between them to behave in a way that shapes and maintains their society.

lives. It is utopian, failing to recognize that it is not of use in unequal relationships and that consensus is never universal. Therefore classical discourse ethics can take advantage of whole classes of persons. It can lead to a preoccupation with the moral minimum of rights and obligations, and it can exacerbate the expert-lay divide. Under such a contract view, the physician's job is to provide a service and information to make a decision. One doctor sums it up this way: "In this increasingly tangled web of experts and expert systems, a doctor has an even greater obligation to serve as knowledge guide" (Gawande 46), and once that is done, the doctor has fulfilled the contracted obligation. The expectation in return is well-behaved (compliant) patients, or at least patients who own their decisions enough to not blame the doctor for unfortunate outcomes. The problem with the contract in this situation is that it is based on an exchange between equals, but one of the underlying assumptions of biomedicine is the hierarchical patient-doctor relationship.

Part of the problem with health decision guides is that even though they seem to promote informed choice by patients, it is often difficult for doctors to recognize the potential for shared agency. The traditional hierarchical roles of patient and doctor are entrenched, and this ordering of relationships has created doctors who feel that it is incumbent upon them to manipulate the patients. A guide developed with a standpoint methodology would take a different approach. If it acknowledged that the only expert in being you is you, and your knowledge is informed by experience in context and your social position (race, class, gender, health status), then it would necessarily call on you to play a greater role in your care and health decision making. Health decision guides can help patients figure out for themselves what they need. Two characteristics of feminist standpoint theory that could be applied to health decision guides are resisting binaristic, hierarchical thinking and acknowledging the cultural construction of knowledge—the idea that knowledge is political and that certain



kinds of knowledge are validated and not others. This type of guide would acknowledge the diverse standpoints of the readers, not just reinscribe science on them.

What I am arguing for is health decision guides that reflect a more complex understanding of the patient-doctor relationship and risk communication—something more useful to real-world decision making than dichotomous thinking that widens the expert-lay gap and gives us the simplistic pro/con chart. The rhetorical problem is similar to that found by Sauer in her mining study: “To find the full range of communication practices . . . so that individuals can make strategic interventions to evoke more complete . . . accounts of the complex interaction of events, decisions, and conditions . . . and so that they can understand what is lost or rendered invisible in written documentation” (2003, 16). By being framed by the biomedical model, some things are getting disciplined out of the knowledge that decision guides could play a role in developing. Health decision guides that ignore the standpoints of patients make them one of the “excluded groups” that Hartsock refers to. This exclusion gives a distorted view of patients’ experiences. What if in revising health decision guides, we wrote them from the standpoint of the othered, the patients? Might such texts help patients trying to see how their life world fits with the biomedical world? Shari Stone-Mediatore says, “Those life stories that struggle to articulate and contextualize experienced contradictions can offer images and narrative matrices that help readers view the same world with a different focus; that is, to ‘see’ their familiar world with greater sensitivity to elements unintelligible within hegemonic history” (123).

With a shift in standpoint, or at least an acknowledgment of the differences between those of doctors and patients, we can begin to do two things: (1) recognize the limitations of social contract theory and consider an alternative and (2) turn the patient as “other” into patient as “co-agent” by making the guides more interactive. The task of the remainder of

this chapter is to offer examples of what this would look like. If chapter 3 demonstrated the weaknesses of the traditional techniques of medical discourse for this genre, this chapter will try to show how health decision guides can mediate two cultures and help “local knowledges [because biomedicine is itself a local knowledge system] travel from one culture to another,” linking to produce new knowledge (Harding 2000, 253, 255). Because “genres both reflect and create the ideas, interests, and values of those who participate in them and use them for particular ends” (Dias et al. n.p.), there is a place in health decision guides for representing both the biomedical world and the life world of patients.

This revised philosophical framework is a natural extension of the ongoing shift in patient-doctor relationships (see Narayan and Harding ix). In this case, I propose a shift from traditional social contract ethic to a feminist ethic of care, or perhaps a blending of the two. The Mayo Clinic early-stage prostate cancer health decision guide meets the minimum obligation of the patient-doctor contract—it provides information on all treatments options. In return for this offering, doctors expect the patient to take part in making the treatment decision. The guide can do better than this, operating from an ethic of care, by not expecting reciprocity, not expecting patients to listen and behave, but by helping them to discern their own knowledges and co-create meaning (decisions that make sense to them) in their particular contexts.

### **An ethic of care**

A natural result of creating a patient-centered guide and reflecting on standpoint theory is adoption of an ethic of care. The theory of an ethic of care stems from feminists’ claim that traditional moral theory does not take into account women’s moral experience.

Virginia Held's concept of this feminist ethic of care is based on the idea that "mother's attentive, creative nurturance of her child may provide a better model for social relations than the fair contract in a free market provides" and that the mother-child relationship is evidence that not all relationships are guided by self-interest and egoism (the values that she sees underlying traditional social contract theory) (Meyers 630). The essentialist underpinnings of this view are problematic and feminists acknowledge that, but Held and others say that these limitations need not stop us from theorizing: We may judiciously use the essentialist argument "women think differently from men" (e.g., emotional versus rational) as long as we do not say that the tendencies should be reinforced (633). The discussions of moral theory in articles by Held, Seyla Benhabib, Carol Gilligan, and Annette Baier each acknowledge the essentialist character of an ethic of care but hold it out as a useful model nonetheless, handled with care. That means that even though an ethic of care is rightly criticized for several reasons, if we examine it with the intention of not reproducing the oppressive situations from which it springs, it can be a valuable addition to the moral theory of feminists and traditional ethicists.

Each of the feminist scholars mentioned above is interested in a theory that reflects the experience and standpoint of women (Held 633), the "other" so often "unthought . . . unseen . . . and unheard" in traditional moral theory. This feminist theory of the private realm is suitable for other domains as well. I propose that it would be of use to health communicators stuck in a mode of discourse in which the patient is viewed as other. Following are three of Held's assumptions about traditional moral theory that feminists challenge, and their suggested alternative. By substituting *patient* for *women* in the next two paragraphs, it is possible to see how this theory fits my purposes as well: (1) Women are morally inferior owing to biological differences [in the patient-doctor relationships, the

patient is diseased and the doctor is not]. (2) Moral theory is best developed in the public realm. (3) Theory should be imposed on experience. And Held points out some inadequacies of traditional moral theory: It does not consider experiences of relatedness, responsibility for growth, empowering of new life, and responsiveness to particular others (639), and it does not consider experiences of women and children (mainly because it was developed for situations in the public realm, and throughout most of our history, women and children remained in the private realm).

In contrast Held and other feminists embrace these assumptions as underlying a feminist ethic of care:

- Women's experience is as valid as that of men (Benhabib 632).
- Women are more likely to exhibit a care ethic than are men.
- The moral judgments and decisions of women are as valid as those of men (632).
- The context of our experience affects our moral choices.
- Experience should determine the theory.

The discussion of Carol Gilligan's feminist moral theory and ethic of care and Lawrence Kohlberg's moral theory and ethic of justice in Seyla Benhabib's essay "The Generalized and the Concrete Other" sets up many oppositions—embodied vs. disembodied, interactional vs. universalistic, rational vs. emotional, and so on (739). One of the most interesting to me is the idea that in an ethic of care decisions are made under recognition of others' needs and wishes, whereas with traditional moral theory's ethic of justice, decisions are made under a "veil of ignorance," as in blind justice. Both styles of decision making have been employed for a very long time, one in the private domain, one in the public. In the public realm, justice is centered on a public standpoint with an image of everyman as a quasipublic personality with inalienable rights—the same rights that every other man has.

From this standpoint, ignorance of any person's individual needs or situation guarantees equal treatment for all. Kohlberg's view is that any decision we make should be one that we ourselves would be willing to live with. Gilligan says, "Kohlberg . . . sees the silent thought process of a single self who imaginatively puts himself in the position of the other as the most adequate form of moral judgment" (747). She points out that the problem with this veil of ignorance view is that it assumes a rational thinker could make a decision that would be "acceptable for all at all times and places" (747). Benhabib says that is impossible. We cannot evaluate moral situations without knowing the situation of the people involved—their "histories, attitudes, characters, and desires" (747). One key element of her ethic of care that she says makes it a more effective moral theory is the idea of the *concrete other*. This idea surfaces in Held's work as the *particular other*. Both terms capture the idea that we need to recognize people in context, in their personal situations, relations, histories, and identities of race, class, and gender in order to answer questions of morality and determine how to "guide, maintain, or reshape" relationships in a way that achieves harmony. A particular other need not necessarily be known to you personally, but you do need to consider the object of your moral decision making as something more than an abstracted rational being on par with all other abstracted rational beings (Held 636).

### **Traditional theory and feminist theory: Complementary or incommensurable?**

Benhabib is not interested in building a theory solely around the concrete other, and she discusses several reasons for the necessity of employing the concept of the generalized

other. But she says that the two viewpoints must be used in concert: “I would argue . . . for the validity of a moral theory that allows us to recognize the dignity of the generalized other through an acknowledgment of the moral identity of the concrete other” (748). Held also recognizes the usefulness of the universal other and believes that without any universal principles at all we are left with capriciousness and chaos. They see feminist moral theory as not replacing traditional moral theory but as concerning more than the moral minimums of rights and obligations that traditional moral theory is preoccupied with. Feminist ethics offer much more than that minimum and cover more domains than the polis and the egoistic individual’s struggle within it, but the feminist ethic still needs the traditional theory. Held argues for a more pluralistic view of ethics—contextual ethics, different ethics for different domains (e.g., international affairs, family relations, the marketplace, the book club).

### **The feminist critique of an ethic of care**

Feminist theorists recognize the problem of essentialism in their ethic of care and the idea that mothers are naturally caring beings. This ethic of care presupposes gender differences that determine behavior differences. And because this discussion has been ongoing since the 1980s, many other theorists have weighed in on feminist ethic of care and offered other critiques and remedies. One remedy to this problem is to understand gender differences to be largely socially constructed (Dombrowski 2000, 64). Paul Dombrowski summarizes several other concerns that feminists have expressed about the feminist ethic of care based on mothering, friendship, and nursing:

- It confirms stereotypes.
- It distances women from “legitimate” ethics.

- It ignores oppressive conditions in which caring occurs (subordinate, dependent relationships of nurses and mothers).
- Care is not reciprocated—it occurs in limited sorts of relationships.
- It perpetuates the idea of biological determinism—constraining expectations of women and denigrating divergence from expectations

(64)

In *Feminism, Foucault, and Embodied Subjectivity*, Margaret McClaren adds these comments to a feminist critique of the care ethic:

- It romanticizes relationships as always nurturing and caring.
- It was formed under paternalistic oppression and serves paternalistic needs (e.g., care done in hierarchical settings).
- It reinforces stereotypical gender roles (such as care and nurturing, which are typically associated with women).
- It assumes a false universalization, neglecting race and class differences.

(79)

She offers these possible beginnings of a remedy, a feminist theory of subjectivity, which acknowledges that “relations of power shape subjectivity” (79). These relations begin with the body, and are grounded in real, historical, material practices and institutions. Such a theory needs to focus on both systemic and interpersonal change. Peta Bowden is another feminist theorist who has tried to recuperate the ethic of care from such criticisms. She sees value in breaking down the dichotomy of the ethic of care and the ethic of justice. If feminist ethics is characterized by care in the private domain, and traditional ethics is characterized by justice in the polis, she asks, what would happen if we minimized the essentialisms of each and integrated the two? What would a caring public look like? Just because we have not

historically seen one, does that mean a citizenship of caring and egalitarianism should not be pursued or that such a thing is not possible? Other false dichotomies that would merge in such a world are rational/emotional and universal/particular. Jaggar asserts that these are not dichotomies that hold up (385). Rather, they are complementary, they are socially constructed, and sometimes the same: Emotion is a key part of systematic knowledge (385-386). We need to “unite intellect and emotion to yield judgment” (Ruddick 582). In the public realm, this would be a convergence of the ethic of care and the ethic of justice yielding a moral maturity with prioritization of relationships (McClaren 163–164). Some say that in integrating the ethics of care and justice, we can reduce the problem of essentialism in the distinctions between them (Dombrowski 2000, 64). That is, rather than a preoccupation with separateness and equality between individuals (justice), relationships and roles (recognition of identities and life histories of people involved) would be key to justifying solutions to moral problems.

So contrary to Lawrence Kohlberg’s claim that an ethic of care was suitable only for the private realm, for concerns related to the so-called good life, many feminists see a possibility for a broader use of it. Held’s project is to show that “distinctively feminist moral theories . . . are better moral theories than those already available, and better for other domains as well” (632), partly because she assumes that caring men are capable of living out an ethic of care, too. One aspect of this ethic that makes it so appealing may have something to do with its not demanding reciprocity in relationships. Might this nonexpectant service inform practice and activism in a way that the social contract never could? Held offers this example: In a relationship between mother and child, where reciprocity is not possible, the social contract gives us no guidance. But if we don’t seek equality in the abstract sense, the



ethic of care guides us by suggesting harmony in specific contexts between known others (637).

How might this ethic, not being based on religion or law, effect change on both a systemic and interpersonal level? To make judgment about moral actions, whether in relationships or between cities or nations, we need to know the other. Decisions must be made under recognition of others' needs and desires rather than under the veil of ignorance.

An ethic of care as undergirding the patient-doctor relationship and the health communications that mediate it would require us to recognize that patients bring to the relationship different agendas, histories, and types of discourse to talk about illness (Edwards and Elwyn 199). Ideally they would bring into the conversation what they consider essential to their sense of well-being, particularly in relation to lifestyle and quality of life issues. That way decisions would be contextualized—made in relation to the patients' situation, needs, and values (120). The guide would help patients conceptualize their unique story as a key element of the decision making process. Currently, the image of decision making presented in this guide, and in the genre as a whole, is listen, learn, decide. By using health decision guides to draw out personal stories and the meaning patients assign to their experiences, patients will be more able to express their concerns and values and see their relevance to the conversations with their doctors about treatment. In the following extract from an information matrix in Edwards' study of medical decision making, you can see that each party brings essential information that only they know:

	Known to me [doctor]	Unknown to me [doctor]
<b>Known to Sally</b>	<p>Good general health.</p> <p>On no medication or recreational drugs.</p> <p>The drug bromocriptine is a possible treatment.</p>	<p>Previous termination of pregnancy; plans a definitive pregnancy in about three years.</p> <p>Finds my surgery times highly inconvenient.</p> <p>Hates the idea of taking tablets, especially when 'not ill.'</p>
<b>Unknown to Sally</b>	<p>A prolactin level of 840 mu/L is very unlikely to indicate a pituitary tumor.</p> <p>Uncertainty in primary care is often appropriately managed by a "wait and see" strategy.</p>	<p>The likelihood of her having a pituitary tumor is extremely low.</p>

(Adapted from Edwards and Elwyn 214–215)

In a situation like this, the participants need to work out any conflicts between the health professional's knowledge and beliefs and those of the patient, and they need to unearth the priorities and preferences of the patient through discussions and with formal shared decision-

making techniques, such as discernment worksheets in a health decision guide. This is a process of contextualization—bringing the decision into the realm of the patient’s life world.

In a broader context, feminist critic of science Ruth Hubbard calls for scientists to contextualize their work. And as the example above shows, for medical doctors this would mean paying more attention to their patients’ values, families, and psychology—not just charts and tests. It also means recognizing the limitations of their own standpoint and the value to be mined in the depths of their patients’ standpoints.

Harding says that one risk of standpoint theory is that by emphasizing the experience of the subordinate, we abandon “epistemological uses of concepts of truth, objectivity, and good method” (2004, 7). In response she says that rather than using standpoint theory without such epistemological foundation, we need to account for both experience and biomedical knowledge by developing “an epistemology that can account for both this reality that our best knowledge is socially constructed, and also empirically accurate” (10). This echoes the recommendation above to use both an ethic of care and an ethic of justice, and it is in keeping with feminists’ rejection of dichotomous thinking. It is not a matter of either-or, but of both-and.

In such guides, the goal would not be to duplicate doctors’ knowledge in the patient, but to help the patient recognize that “professionals have much to learn from patients as well” (79) because “to confine attention only to what appears to be the hard evidence may well cause more harm than it averts” (82). The successful health decision guide will “build upon and augment the knowledge and experience of lay audiences” (Sauer 2003, 17). In their unique position as boundary objects, health decision guides can mediate two cultures and link participants in a way that produces new knowledge. We can begin by dispensing with the transmission model of communication, relying less on the audience-addressed mode,

adopting an interactive, sociocognitive approach (see Berkenkotter and Huckin) to audience and genre, and creating a “meaning-centered” model (Specker Stone 204) of patient education, drawing out the individual, social, and cultural meanings that the patient derives at the center of treatment.

As mentioned, health decision guides reflect the hierarchical biomedical world and the division of expert and lay. Forest Tyler says that such psychologically dominating communication “is based on a widely shared assumption that human interactions are a one-way transmission of theories, facts, methods, and values from the more powerful or enlightened to the less so” (vii). He proposes that we recognize “we are each involved in formulating a meaningful conception of our life out of experiences and social context. . . . There is an inherently reciprocal situation between each of us and our biopsychosocial context” (viii).

If doctors want patients to learn this world of biomedicine, if any nonhierarchical productive relationship is to develop, they need to do what Jaggar recommends for anyone attempting border crossing: “They need to ‘know the text,’ to have become familiar with an alternative way of viewing the world” [their patients’ way] (2004, 64). This could lead to a transformation of power relations and may help doctors and patients realize the full potential for shared agency, especially if they recognize agency not as a thing, something you can hold onto, but rather as shifting with the place, time, and position of a structure—as something you can cycle in and out of. Bringing to a physician consultation a patient-centered health decision guide developed on these principles would be like bringing a friend. Bringing a guide like the one reviewed in chapter 3, one based on biomedical assumptions and a

traditional social contract, would be like bringing another doctor into the room.<sup>41</sup> That's because when knowledge claims of physicians are privileged, as they are in most such guides, we "work against real collaboration between patients and physicians" (Specker Stone 212).

### **New practices for an interactive approach to health decision guides**

If by promoting an ethic of care we are encouraging doctors to contextualize their work by considering their patients' values, families, and psychology in decisions related to medical treatment, then it follows that the health decision guides that mediate the patient doctor relationship also take these factors into consideration and not just present probabilities and statistics. If we are to truly find available means of persuasion and not just bombard people with facts (fulfill the contract), we must also draw out embodied knowledge by genuinely guiding patients through a discernment process that incorporates their contextualized knowledge, in addition to the contributions of biomedicine and doctors' clinical practice experience. It is good that we include biology—it is an important basis for assessing risk (see Sauer, 2003, 13, footnote 29), but biology alone is not enough. Craig Waddell puts it this way:

If we broaden our concept of rationality . . . to include emotional as well as logical appropriateness. . . . to encourage wider acknowledgment and acceptance of the extent to which our concept of rationality is already shaped by our sense of emotional as well as logical appropriateness. . . . From this perspective, the question to ask of a

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<sup>41</sup>If health decision guides are to facilitate patient agency, they must increase patients' competence, "their capacity to produce expressions which are appropriate for particular situations" (Bourdieu 7). Health decision guides should help them to "produce utterances that are . . . tacitly adjusted to the relations of power between speakers and hearers" and help them "develop the capacity to make oneself heard, believed, obeyed, and so on" (7, 8).

behavior, judgment, decision, appeal, or response is not “Is it rational?” or “Is it emotional?” but “Is it appropriate?”

The social construction of appropriateness, however, is not simply a process of noble rhetors enlightening their audiences . . . rhetors and audiences together co-create meaning and values through the given-and-take of epistemic rhetoric. (394)

Borchers expresses similar sentiments toward the mere transmission of facts: “Persuasion is a process instead of a simple one-way transmission. Persuaders create messages, to be sure, but the persuasive process is incomplete until the audience becomes involved” (17).

Specifically, in relation to the guide analyzed in chapter 3, I suggest that we begin by first centering the patient, certainly with a simple organizational change such as placing the patient stories before the “Meet the Doctor” section, but more importantly with an intrinsic change that puts the patient at the core of the whole guide, making the guide by and for readers. If the current guide views the user as a mere information consumer, a re-envisioned guide will view patients as active users, interpreters, and creators of meaning. Ask them, “Is there anything special you want as a reader?” (Blakeslee 2001, 66) and develop a means for ongoing audience feedback and incorporation of that feedback. Rather than readers merely accepting the general authority of information in health decision guides, authors can encourage them to see information creation as being at play, constantly affected by communicators’ values, interests, and social dynamics (Berkenkotter and Huckin 96)—and, from a feminist standpoint, even emotions. A guide that starts to get at a patient-centered approach might include concerns such as: How much do you really want to know (e.g., in relation to survival statistics)? How involved do you want to be in the decision-making process? Are your expectations realistic? Are you willing to accept help from others? Are you willing to stick up for your own beliefs and feelings in the face of pressure from others?

What are your goals for treatment (e.g., cure? urinary continence? a sex life, even if that increases the likelihood of your having a shorter life?). This sort of guided discernment process must also present the option of not being involved in the treatment decision-making process at all, or even of refusing treatment altogether.

Let me give one example of a health decision guide that has taken a significant step toward this patient-centered model of meaning creation, especially in its efforts to help patients recognize the subjective aspects of the decision, such as how important each benefit or harm is to them. The HealthMark decision guide on early-stage prostate cancer (mentioned in chapter 1) is a multimedia CD. It views its users as outside conventional science, not as junior doctors. It acknowledges that readers bring with them values, opinions, and experiences. HealthMark's format does not have enough text to give the authors a place to constitute an implied reader, so instead they effectively rely on an interactive approach—inviting the reader to respond to information presented in the document (mostly in the form of diagrams, charts, and lists). For example, possible outcomes are not presented in a pro/con chart but rather in a list. The reader is asked to consider whether he thinks each listed item is a pro or a con and then to prioritize them (see appendix C). Giving patients more places to plug in their own variables and to discern their own values related to potential outcomes and side effects is empowering. It helps them become truly active players in their treatment plans. A patient's personal values and goals will make all the difference in what treatments he or she determines are best. A revised guide might also include elements such as questionnaires, values discernment worksheets, and calculator tools that allow patients to enter variables

unique to them. To be even more interactive, it might offer hotlines, chat rooms<sup>42</sup>, and online events such as “Chats with the doctor” or a panel of patients.

Each of these methods would fulfill Sauer’s call for a more complex understanding of documentation practices: “Decision makers need tools to sort through the complexity, and they need rhetorical knowledge to understand how audiences construct and negotiate meaning as they communicate with others in their work” (2003, 16). I propose that such an approach will result in a genuinely useful discernment guide that results in decisions that are based on the contexts of patients’ life and work. It would shape it into more of a genuine *guide* book and less of a textbook. As is, in the Mayo Clinic early-stage prostate cancer guide under investigation, the term *guide* is something of a misnomer.

Practical recommendations related to balancing appeals to logos, pathos, and ethos (though adopting the ethic of care described will take us a great way toward that goal already) might mean presenting anecdotal evidence on equal terms with evidence-based medicine. Health communication researchers David E. Nelson and his co-authors say, “Scientific methods and reasoning are unfamiliar to many people; instead they often rely on personal experience, stories, and emotion to make health decisions” (5). Treatment decisions are affected by whether readers understand the statistics in the health decision guide:

Both treatment success rates and the percentage of patients experiencing side effects are difficult to evaluate in the absence of comparative information. Thus patients may be prone to choosing treatments that are minimally invasive or less costly (attributes that are easy to evaluate) because they cannot assess the relative value of a particular success or side effect statistic. By the same token, personal anecdotes (“my sister had

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<sup>42</sup>The obvious risk for Mayo in such interactivity is that the more interactive a site is, the less control of the site Mayo has.



that done”) will influence patient decision making the most when quantitative comparisons of other attributes are difficult to perform. Only when all alternatives are presented concurrently will such hard-to-evaluate information be fully integrated into choice processes. (Zikmund-Fisher, Fagerlin, and Ubel 146)

Such an approach might help to prevent an overreliance on the anecdotal and the paralyzing effects of too much data.

### **Other recommendations for patient empowerment and author credibility**

The recommendations of this chapter overall have been intended to increase patient empowerment and interaction between author and audience. Let me add four additional, very practical recommendations. The first three of which would be quite simple to implement, the last one of which would require a good share of planning:

- Include a bibliography and citations and maybe even provide links to the evidence-based medicine articles available online.<sup>43</sup>
- Add a street address to the site (Freeman and Spyridakis, 253, 258).
- Remove links to advertisements—readers prefer sites that are informational, not commercial (253, 258).
- Involve patients in the review process—at least let those who shared their stories review and revise their own videos and transcripts.

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<sup>43</sup>“Whatever the reason for omitting sources [as *www.MayoClinic.com* does], the result is a disempowering of the reader. Sourcing allows the reader to challenge the article’s contents” (Morrongiello and Straus Reed 22).

### Recommendations for tone and style

Rhetorical performance is at its best when characterized by the coming together of style and content, regardless of genre or context, in a way that suits your audience and also your intentions. The goal is to match the style and tone to the audience so that they are receptive to what you have to say. In order to do this, you must first follow Aristotle's advice to know your audience (or imagine who you think it is), determine what speech is available, and fit the two together. The producers of this guide have chosen something between the typically scientific style and a more popularized style, which is appropriate because as I mentioned in my audience analysis, the readers of health decision guides are not your average magazine reader, nor are they medical journal readers. They are highly motivated people. As a result overall this guide has a textbookish look and plain (*docere*, which means "to teach") style. Its word choices reflect the "sober ethos of reserved and dispassionate science" (Gragson and Selzer 31). Nominalized diction (insider's language, such as that in the doctor interview), syntax, and use of the passive gives the appearance of objectivity (Couture and Kent 104) and "locates the article and its readers in the domain of conventional science" (Gragson and Selzer 31). Haraway comments on this conventional scientific writing style: "The subject of knowledge claims was to be an idealized agent who performed the 'God trick,' speaking authoritatively about everything in the world from no particular location or human perspective at all" (quoted in Harding 2004, 4). Especially in the treatment section, I see increased use of scientific habits of "qualified, guarded, conditional language" (Gragson and Selzer 31). But the style varies with the speaker—the doctor is more formal, the patients who share their stories are more informal, as if talking with friends.

I would suggest reducing the formality of the text, beginning with the introduction. It might be more inviting and empowering to remove the imperatives (Give . . . , Learn . . . ,

Find . . . , etc.) and put the reader in the position of doer, not learner, for example, “As you approach a decision, you will be gathering, learning, seeking, discerning. . . .” Other suggestions for lightening up the conventional scientific style would be to use an informal tone, rhetorical questions, dashes, a little more personality from the author, contractions, and conjunctions at the beginning of sentence. The treatment section does use “you” in reference to the reader, and it does use contractions liberally. Otherwise, these habits of informal writing are generally avoided in the guide.

Sometimes the pronoun “we” is used in the guide to boost identification. In the welcome section, the author’s use of “we” to refer to the author and readers serves this purpose. But in the “Meet the Mayo Doctor” section, “we” is used in reference to the doctor and his colleagues, not the patient and doctor: “we gauge,” “we can select,” “we can use our best estimate.” The doctor also refers to patients as “one” rather than “you,” which may further foster an us-and-them attitude. Other suggestions for the “Meet the Mayo Doctor” section are as follows:

- Increase credibility by including doctors from each relevant specialty (in this case, urologist, oncologist, and radiologist), not just a urologist.
- Place it following patient stories, if your goal is to create a patient-centered guide.
- Blend tone better with other sections. Maybe give the doctors some pointers, such as, rather than saying, “We have many ways to treat,” say, “You have many treatment choices available.”
- Make it more of a patient-doctor question-and-answer session than an anonymous questioner and only one doctor.

In this genre, the successful blending of style and content is especially important in the presentation of biological data. A guide may contain a clear summary of the best medical

literature available, that is, depth of information. But if it is presented in just one way, for example, in paragraph after paragraph of plain, gray text, the guide will not meet the needs of its wide and varied audience. Risk statistics and other biological data are best communicated in multiple ways, including with numbers and graphics. To present statistics in a useful way, as Nelson and his co-authors suggest in *Communicating Public Health Information*, we must consider that “the implication of low math literacy and interest is that most people will not be persuaded solely by logical, number-driven arguments; presenting more data and facts to such audiences is likely to be counterproductive. This does not mean that public health professionals should not use quantitative information; it does mean that such information needs to be translated into a form appropriate for the intended audience” (5).

It may take more time and money to produce, but the best solution might be to present the probabilities and risk statistics of evidence-based medicine in a variety of formats to meet the diverse learning styles of the readers.<sup>44</sup> One bit of data might be presented in three forms, such as prose, pictograph, and chart. Perhaps these graphics would be clickable so that each patient could choose the format that appeals to him or her. The presentation format chosen will be a function of the goal of the interaction and how well the author thinks the readers will be able to interpret the information. Before I get too far afield, let me admit that these concerns, though valuable to a successful re-envisioning of health decision guides, are secondary to the main concerns of this thesis. For more on revising the approach to biological data in decision guides, see appendix D.

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<sup>44</sup>“The living brain very much appreciates intelligence expressed in different forms” (Montgomery 14).

### **Recommendations for personal stories**

Anecdotal evidence is highly valued by readers. And the Mayo Clinic guide analyzed in chapter 3 has done a good job of including the stories of men who have gone through the decision-making process for early-stage prostate cancer treatment. The stories succeed in presenting a range of treatment options, but could do better by representing men with a wider range of attitudes toward biomedicine and of decision-making styles. As mentioned in chapter 3, the five men profiled in the guide all seem to tow the party line. Perhaps it would increase ethos in the sense of identification if it included someone who has a fear of doctors and hospitals or who is dissatisfied with his outcome or someone who followed a very different decision-making process than the one used by these five men. I would also suggest providing more examples of each treatment option and including more easily identified points of identification for the readers—such as age and stage of disease—so that they could quickly find the story that most closely parallels their own. The guide might also increase its ethos by including testimonials of men who had a bad experience with the medical establishment and have advice on how to go about things differently.

### **Conclusion**

The theoretical and practical recommendations presented here for re-envisioning more patient-centered health decision guides are a start to easing the decision-making concerns of patients of all types. But as Harry Collins points out, “There is no magical escape from the pangs of uncertainty that underlie our decisions” (quoted in Myers 2003b, 607). In their exploration of uncertainty in illness, Babrow and his co-authors say,

Our ability to understand illness and health communication requires attention to variations in meanings of the term *uncertainty*. Effective response to illness depends

on the ways that patients, loved ones, and health practitioners understand and co-construct the many uncertainties that comprise the illness experience. Talk about the future course of an illness, alternative therapies, and competing and conflicting goals . . . entails a complex interactional weave of multiform uncertainties. When we ignore these complexities, we limit chances for effective action. (3)

It is not enough to make decisions on statistics alone. Values and rules of conduct—both those of patients and those of the doctors—play a role too (Edwards and Elwyn 81). For example, “What obstetricians perceive to be the risk of giving birth to a deformed baby can, from another angle, be seen as a threat to the rights to life of disabled people” (Shakespeare, as quoted in Edwards and Elwyn 81). How do different values of doctors and patients affect treatment choices? Decisions are inevitably and rightly swayed by personal values. That’s the patient’s dilemma. And that’s where the re-envisioning of decision guides proposed in this paper can help lead to development of health decision guides that empower patients to arrive at the best possible decisions given that uncertainty is a constant.

## **Chapter 5**

### **Implications and Future Studies**

The patient-centered theory and practice suggestions I have made in chapter 4 will, I think, benefit and empower patients. But let me point out how such changes to health decision guides would be of advantage to doctors and health care institutions as well. For doctors, improved guides will reflect and further bring about the ongoing shift in patient-doctor relationships. I propose, as Specker Stone's study of the rhetoric of patient participation in health care points out, the tension between patient and doctor inherent in the practice of medicine would benefit from a relationship based on more than a mere social contract and more than submissive patients. Recognizing and respecting local situations is essential to connecting with your audience (i.e., patients), and real relationships require much more than following universal rules (i.e., the social contract). By creating "an atmosphere conducive for patients to participate in communication and decision-making with their doctors" and welcome them "with language, respect, and information necessary to move them into agency" (Specker Stone 213), doctors may rethink their identity and recognize that it shapes relations. They may be more open to reinterpreting their assumptions and values and recognizing the potential for shared agency. Doctors may even find a certain amount of freedom in letting go of the need to present a univocal front to the public. Even the Federal Drug Administration, in dealing with its Vioxx crisis in 2004, has come to realize that sharing more information is better than sharing less. By going public with its debates and conflicting reports, it invites doctors and patients into the conversation and demands from them a certain degree of responsibility for their own decisions. The public does not need to

be protected from the uncertainty that is an inherent part of the highly contested, political world of biomedicine.

For health care institutions, which are primarily responsible for producing such guides, adopting the feminist and rhetorical approach outlined in this thesis is to meet the challenge of Mirel and Spilka, who urge them “to take the reality of the communal nature of learning and working into account as we build products and develop the communication within and for that product” (xii). And they will benefit by adopting a rhetorical perspective toward their particular genre and accepting Berkenkotter and Huckin’s thesis that “genres are inherently dynamic rhetorical structures that may be manipulated according to the conditions of use, and that genre knowledge is therefore best conceptualized as a form of situated cognition embedded in disciplinary activities. For writers to make things happen (i.e., to publish, to exert influence on the field [or patients], to be cited), they must know how to strategically utilize their understanding of genre” (3)

Another benefit for health care institutions will be an enhanced ethos, not just the traditional discursive form of ethos but also in the sense of communal ethos—the nondiscursive form. The guide’s “place” on the Web will be somewhere people turn to first and identify with. For example, in Mayo Clinic’s case, the information on Mayo Clinic’s health information Web site is available from other sources on the Web. So what is going to set apart this site, aside from Mayo’s not inconsiderable influence and weighty seal of approval? It will be the site of choice if it offers more than information but also guidance, ethos (both discursive and nondiscursive), community, and help in culling good information from bad, for example, by offering the minitutorials mentioned in chapter 4. Mayo can be the most trusted and most interactive (i.e., identified with) site—the most respected yet also the most respectful of and responsive to reader’s life worlds, values, and experiences.



These advantages of course cannot be proven without further study, especially over time. Long-term usability studies are opportunities for fostering reciprocal responsiveness between author and audience. They are also vital to determining the effectiveness of guides and their influence on outcomes and health care costs.

### **Future study**

An aspect that I did not touch on in this thesis is the role of technology and the opportunities offered by a Web-based format for such guides. How can producers of health decision guides take advantage of the Web's potential for interactivity and information tailoring? Carolyn Miller, in an article on human-computer interaction systems, offers some interesting ideas for the future. She points out that the "interface is critical, perhaps more critical than any other component" for users will need to sense that they have a relationship (2004, 210). She continues:

Cyborg discourse, I am claiming, presents a contemporary model for the Ciceronian ethos of sympathy. An ethos of sympathy emphasizes the Aristotelian component of *eunoia*, finding its rhetorical ally in *pathos*; it focuses our attention on the interest that a rhetor has in us, in the audience's feelings, needs, sensitivities, and interest. An ethos of sympathy is always looking for a response and Zeno's image of rhetoric as an open hand represents its character well. (Quoted in Hyde, 212)

In short, it needs to be user friendly. It will be interesting to examine the production processes of such guides in light of this need for identification and sympathy that readers seek in community, even an electronic community. Rhetorician John Trimbur advises us to pay attention to the relation between production, distribution, and consumption. We can do this with long-term studies, for example, by interviewing men who are healthy, newly

diagnosed, and post-treatment (five, 10, 15 years out). Such studies over time would allow us to follow the evolution of health decision guides and whether they reflect or help to bring about a shift in doctor-patient relationships, whether they affect the effectiveness of health treatments, or the satisfaction with one's decisions, and perhaps even information on how medicine changes as the discursive practices of doctors change (other such long-term studies have yielded valuable insights along these lines. See Bazerman [1988] and McCarthy and Gerring). Without such long-term studies, we will not really be able to determine whether health decision guides are actually doing what we are expecting of them. Health care institutions and insurance companies will be particularly interested in learning whether such guides affect health care costs and access to care. When people know of all the options available, to what lengths do they go to obtain or demand that care (e.g., the cutting edge procedures like cryotherapy and robotic laparoscopy described in Mayo's early-stage prostate cancer health decision guide)?

### **Usability studies**

The health decision guide genre offers a wide range of opportunity for further study, not only because so much has been left unexamined but because as the site of three intersecting systems—medical, communications, and the life world of patients—it is an ongoing, fluid, “blurred and emerging” genre (Myers 1996, 28). At the juncture of medical settings and patients' life worlds, it both reflects and continues to shape the redefining of roles that professionals and patients are engaged in. At the site of medical and communication worlds, the places where motives and goals of writers and scientists meet, it creates “documents that are linked to dynamic and historically evolving discursive practices” (Berkenkotter and Huckin 328).

As mentioned in chapter 4, an interactive approach to audience will require us to affirm “the importance of knowing their audience and of the need for a long-term multifaceted approach to becoming acquainted with their readers” (Zepernick 244). In the case of health decision guides, I think that usability studies of each guide separately would be most useful if the goal is increased interactivity, that is, reciprocal influence, between producers and users. It is important that health decision guides be responsive to the people who use them—doctors, patients, and caregivers—and that they change as the discursive and professional practices of doctors and patients change. It might be productive to involve users in the revision process. The aim would be a “critical research perspective that aims at empowering participants to become collaborators in research” (Scott 199). Technical communication is an “ongoing cultural process through which linkages of power create meaning and shape identities” (199). Various approaches to usability studies have been tried (e.g., Turns and Wagner 2004, Fagerlin et al. 2004), and some have offered advice on what types of studies to use (Cline and Haynes 2001) and how to conduct an interview, because it is not easy to design good questions.

Usability studies on each guide may tell us how to tailor the information and presentation to better meet the needs of the readers. Should we offer multilingual versions? Should we offer multiple entry points, for example, for newly diagnosed and for follow-up, or for people of different ages? How does use vary as far as frequency, expertise, reasons for using? Can the readers see themselves in the statistics we use, that is, do the figures reflect age, race, disease stage? Can the users see themselves in the personal stories? We might also learn how decisions were affected by the information provided, whether the information was useful, how users acted on the knowledge they acquired from health decision guides and whatever counseling accompanied it. We might find out how health decision guides should

differ for mental and physical conditions. For example, if informed consent isn't possible due to a mental condition, do health decision guides need to be addressed to family members? How would guides for family members differ from those for the people who are sick?

In developing our plan for future studies, we must draw on all available resources. Specker Stone and Segal criticize health information researchers for not drawing on rhetorical theory. And Sauer criticizes rhetorical theorists for not using the studies of research specialists to learn more about decision making in uncertain, dynamic situations. She says, "At the most obvious level, risk specialists can help rhetoricians elicit what audiences know and how they structure their understanding of complex issues" (14). This research might ground and inform a usability study of health decision guides. It might show that such studies would not be fruitful in answering our questions. It might help us to understand what we need to learn from the users of our documents.

Many other aspects of decision making, risk communication, and visual rhetoric (e.g., the shift toward information design—the synthesis and presentation of information) relate to this discussion. But owing to a desire to focus on the author's approach to audience and patient agency, I have left those as limitations of this study and fodder for the next. Results of future research will help to generate patient education materials that take advantage of the opportunities offered by a Web-based format and that yields writing that serves both expert and lay readers. Improved guides may also help the general readers of health information understand the highly contingent and nonstable nature of medical research and knowledge. The hope for the lay reader is that the medical world is not monolithic—there is not just one right way to do things (Hilgartner 533). Effective health decision guides can help show that and, more importantly, help patients choose a treatment that they are comfortable with.

## Appendix A

### MayoClinic.com Home Page

MayoClinic.com - Medical and health information and tools from Mayo Clinic

Page 1 of 1



Mayo Clinic Medical Services | Mayo

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#### Health Centers

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[Alzheimer's](#)  
[Arthritis](#)  
[Asthma](#)  
[Baby's Health](#)  
[Brain & Nervous System](#)  
[Cancer](#)

#### First-Aid Guide

#### Quiz

**Alcohol-use quiz: The cost of crossing the line**

What percentage of Americans ages 12 to 20 use alcohol in a typical month?

- ☐ 8 percent  
☐ 17 percent  
☐ 28 percent  
☐ 39 percent

[Submit](#)

#### New Year's resolutions: Strategies from Mayo Clinic specialists

Can't decide on a New Year's resolution? Get some ideas from eight Mayo Clinic specialists.



#### Timely Topics

- [Seasonal affective disorder \(SAD\)](#)
- [Prostate cancer prevention: What you can do](#)
- [Vioxx, Celebrex and Aleve: What's a consumer to do? Editor's note](#)



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Visit [Brain & Nervous System Center](#)

#### Health Tools

##### Slide Shows

From allergies to weight training, arthritis to stretching, let us tell you the story in pictures.

##### Health Decision Guides

Use our tools to help you make the best treatment choice.

##### FEATURED TOOL >>>



**Tool: Daily calorie calculator**  
Calculate the number of calories you need each day to maintain your weight.

#### Today from Ask a Specialist

**Q.** Is it safe to eat potatoes that have a greenish tinge?

[Read the answer](#)

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## Appendix B

### Early-Stage Prostate Cancer Decision Guide Home Page

Opening page of Mayo Clinic's early-stage prostate cancer health decision guide on its health information web site, [www.MayoClinic.com](http://www.MayoClinic.com)



Mayo Clinic Medical Services | Mayo

[Log in](#) | [Register now](#) | [Site map](#)

[Home](#) | [Diseases & Conditions](#) | [Treatment Decisions](#) | [Drugs & Supplements](#) | [Healthy Living](#) | [He](#)

#### Early-Stage Prostate Cancer \ Health Decision Guide

FORMAT TO PRINT: [This section](#) | [All sections](#)

##### IN THIS DECISION GUIDE

##### Welcome

- [About prostate cancer](#)
- [Treatment options](#)
- [Meet the Mayo Clinic doctor](#)
- [Personal stories](#)
- [Things to consider](#)
- [Dictionary](#)
- [Related links](#)

##### Welcome

By Mayo Clinic staff



Receiving a diagnosis of prostate cancer can be scary. It can lead you to fear, panic and hurried decisions. You may even feel that you need to make an instant decision and begin treatment right away. However, most prostate cancer is slow growing, so usually there's no need to rush.

Instead, give yourself time to gather information. Learn about all treatment options that are available to you. Perhaps talk to others who've been in a similar situation. And consider seeking opinions from doctors in specialties such as

urology, oncology and radiotherapy. Some doctors are more inclined to recommend a treatment in the specialty that they're most familiar with. Gathering several specialists' opinions may give you a more balanced understanding of your treatment options.

Before reaching a definitive treatment decision, it's important that you understand the pros and cons of the various options in relation to your specific situation. The information in this guide is designed to heighten your understanding of the details to consider. In this guide, you'll watch a Mayo Clinic urologist answer frequently asked questions about the treatments available for prostate cancer. You'll also see and hear from five men, each of whom chose a different treatment option.

It will take about an hour or more to go through this guide. Although it's not essential to do it all in one sitting, it's important to review it before making a treatment decision. That way you may be more fully informed and know what to expect.

When you're involved in making decisions about your treatment, you're more likely to feel better about it, you'll have a better sense of control and less anxiety, and you'll feel more able to cope and more able to talk about your disease and its effects with your loved ones.

The information presented here is designed specifically for men with early-stage prostate cancer, not advanced prostate cancer. See the "Related links" section of this guide for information about advanced prostate cancer.

[Next section >](#)

September 28, 2004

PC00001

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## Appendix C

### HealthMark Pro/Con Chart

Sample pro/con chart from HealthMark multimedia CD *Prostate Cancer: Your Decision Notebook*

## Prostate Cancer: Your Decision Notebook™

**Watchful Waiting - Personal Concerns**

Pros & Cons <small>Personal Concerns</small>	I consider this as:			Importance to me:	
	Pro	Con	I don't know	Not too important	Very important
Cancer will be removed from body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<div style="width: 100%; height: 10px; background: linear-gradient(to right, black 50%, white 50%); position: relative;"> <div style="position: absolute; left: 0; top: -5px; width: 10px; height: 10px; background: white; border: 1px solid black;"></div> <div style="position: absolute; right: 0; top: -5px; width: 10px; height: 10px; background: white; border: 1px solid black;"></div> </div>	
Side effects will be minimal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<div style="width: 100%; height: 10px; background: linear-gradient(to right, black 50%, white 50%); position: relative;"> <div style="position: absolute; left: 0; top: -5px; width: 10px; height: 10px; background: white; border: 1px solid black;"></div> <div style="position: absolute; right: 0; top: -5px; width: 10px; height: 10px; background: white; border: 1px solid black;"></div> </div>	

**Pros**

**Cons**

This information is for educational purposes only.  
Talk to your doctors frankly about all aspects of your illness and treatment before making any decisions.

**HealthMark**  
MULTIMEDIA

© 2001 by HealthMark Multimedia, LLC  
<http://www.yourdecisionnotebook.com>

## **Appendix D**

### **Recommendations for Improving the Presentation of Statistical Material**

As mentioned in the text, when presenting statistical biomedical information, it is important to use a variety of approaches to meet your readers' needs. By acknowledging the varied starting points of your readers as related to their knowledge of and experience with the disease, you will be more able to gauge the range of presentations for each bit of data that you would like to share. Victor Cohn and Scott Montgomery have much more to say on this topic. You would do well to refer to their guides before launching any revision of your mode of presentation of statistical material. One key dictum that they would both agree on is to be wary of studies with only a small numbers of cases, that is, don't trust statistically insignificant studies (Cohn 187-188). That said, consider these recommendations too:

- Provide quantitative information regarding benefits and harms to accompany any verbal presentation. Use easily understandable schematic diagrams that compare existing procedures and treatments with new ones. (Montgomery 72)
- Use comparative presentations that allow both easy- and hard-to-evaluate attributes to receive proportionate decision weight (Zikmund-Fisher, Fagerlin, and Ubel 147).
- Consider the materials' evaluability. Is the reader able to easily compare and contrast crucial factors? (142)
- Compare outcomes of all treatments in a single summary (Fagerlin et al. 721).
- Tailor information for age, race, and stage of disease.
- Add links to minitutorials on decision making, risk assessment, numeracy, and statistics. (See the sample flow chart on page 324 of Rymer, Wilson, and Ballard.)



- Improve patients' ability to evaluate data with techniques such as side-by-side comparison, presentation of a range of values where appropriate, and so on.<sup>45</sup>
- Don't shield readers from uncertainty and the dissensual nature of medicine. Admit when conclusions may be tentative or equivocal (Cohn 59). Offer follow-up, that is, up-to-date outcomes information, on new treatment technologies.

Perhaps the best bit of advice comes from Montgomery: "Come to understand what consumers [that is, your readers] are interested in" (72).

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<sup>45</sup>See Zikmund-Fisher, Fagerlin, and Ubel (142), which found that arrangement is especially important in the presentation of options for comparison. People make decision by comparing multiple options together or by evaluating options presented separately. Studies show that they come up with different decisions depending on which mode is used: joint or separate. The research concludes that this is because of the "evaluability hypothesis," which posits it is more difficult to evaluate the desirability of values on some attributes than on others and that, compared with easy-to-evaluate attributes, difficult-to-evaluate attributes have a greater impact in a comparative presentation than in a single evaluation mode."

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