

BRINGING THE PATIENT BACK IN

Guidelines, Practice Variations, and the Social Context of Medical Practice

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Abstract

We challenge assumptions that have guided much research and policy aimed at understanding and reducing medical practice variation. Paramount is the focus on doctors as the cause of variation to the neglect of other possible influences. Some research literature suggests that patients, families, and the community context of practice may also influence treatment decisions. Failure to question present assumptions, despite weak evidence in support of them, may account for inability to explain persistent practice variation, develop appropriate implementable guidelines, or anticipate the effect on treatment decisions of greater patient involvement. In this paper, we discuss the weak response to the NIH Consensus Conference on early stage breast cancer because it may have reflected these problems. We urge a more complex and more empirical approach in explaining treatment choice and guidelines sensitive to the potential for value differences.

Keywords: Practice variation, Practice guidelines, Consensus conference, Patient preferences, Breast cancer

Few empirical findings have energized as much corrective action as have medical practice variations. Although Glover (29) first noted geographic variation in the 1930s, contemporary concern stems from 1973. In that year, Wennberg and Gittelsohn (87) published data revealing dramatically different surgical rates in neighboring New England communities. The finding that medical treatments varied by locale threw into question beliefs about medicine that lay at its very foundation. These beliefs included that treatments were dictated by clear-cut science, that they were consistent across patients, that they were of dependable high quality and that, being medically necessary, they were financially necessary. If the response of doctors to a given diagnosis varied from one area to the next, the opposite appeared possible: treatments were not dictated by science, were not consistent and of dependable high quality, and payment for them might not be justified medically or financially.

Corrective action focused immediately on the practicing physician. Medical policy leaders embraced four ideas about the causes of variation: a) there is uncertainty in the scientific literature that permits alternative conclusions and applications; b) many medical

practitioners lack the time, training, or motivation needed to analyze the methods and statistics behind competing claims; c) practitioners allow their practices to be directed by personal preference or financial self-interest rather than quality; and d) variation could be attributed to lack of patient involvement in treatment decisions. The first and second hypotheses have motivated efforts to clarify scientific knowledge and to disseminate conclusions. The third has led to attempts to constrain nonconforming practice through regulation, bureaucratic obstacle, or denial of payment. The fourth has led to initiatives aimed at patient empowerment.

What these ideas share is a presumption that practice variations result from the attitudes, behaviors, and local cultures of practicing physicians. In prior analyses, we have provided empirical evidence on physicians' embrace of practice change that confirms the importance of uncertainty in medical decision making (assumption 1), but challenges assumptions two and three regarding the reasons that physicians may ignore practice recommendations (32;33;36;37). Here we address hypothesis four and, more generally, the assumption of physician dominance that is embodied in all four hypotheses. We argue that the focus on doctors as the cause of practice variation has deflected inquiry from other factors that might lead to variation, especially patient and community values.

Others have suggested a possible role of patients in treatment variations. Frustrated by the inability of popular variables to explain persistent variation in breast cancer surgery, Gilligan et al. (28) proposed the need for new variables. They suggested attention to "enduring factors such as the organization of the medical community and patient preferences." Facing the same problem of unexplained variation, Guadagnoli et al. (38) proposed that "additional studies are needed to determine whether variation in practice between geographic areas is due to differences in patient preferences and values or to surgeons' propensity for one type of surgery based on where they practice."

THE ROLE OF PATIENTS IN TREATMENT CHOICE

Over the years, analysts have tended to the view that patients are essentially inert. This assumption is tacit in the work of many economists and analysts concerned with the market behavior of physicians, hospitals, and the healthcare system. In these writings, it is assumed that the "demand" for medical services differs from other demand in that it is produced or elicited by providers rather than imposed by consumers. Doctors control both quantity and nature of service (39;67;87).

The assumption that medical views are implemented with few constraints is tacit in other writing as well. A recent article citing challenges to the delivery of "appropriate" medical care cites as a major problem "the medical profession's historical tendency to view appropriateness in strictly clinical terms" (77). This tendency is illustrated with a sentence from a letter to the editor of the *New England Journal of Medicine*, where a physician expresses the opinion that "the patient's attitude should have no influence on what the physician advises as appropriate therapy for the patient's illness." We are left to infer both that the letter writer holds a typical viewpoint and also that he successfully imposes it on patients such that the attitude becomes "a major problem." No evidence is marshalled for the pervasiveness of the view, the ways in which it prevails, or even what the letter writer actually meant, were the remark seen in context. The statement does not apparently require evidence, only illustration.

If doctors dictate treatment with little regard for patient wishes, this could indeed result in patients receiving care different from that which they might prefer and in patterns of variation different from what would occur if their preferences were salient. Research reveals that doctor and patient values differ. Jennett (41) reviewed data showing that elderly patients place less emphasis on health generally than do doctors (or patients in the prime working

years), are more accepting of disability than doctors (and younger patients), and are less inclined to aggressive treatment. Relative to specific treatment options, researchers have reported that patients and doctors differ about end-of-life treatment choices (14;68;75) and in preference for laryngectomy, where longevity is gained at significant cost to quality of life (58). Additionally, in a study by Veatch (85), doctors did not accurately predict their patients' preferences for life-sustaining interventions. The doctors' predictions corresponded more closely to the choices the doctors would make for themselves than to those obtained independently from the patients.

Braddock et al. (7) have been concerned with whether consent to treatment is truly informed. These authors searched videotaped office visits of primary care physicians and surgeons for elements that the research team proposed as comprising truly informed consent. Against their admittedly high standards, doctor performance was poor. In the literature on breast cancer research, which we discuss in this paper, doctor dominance is considered to operate through two mechanisms. Patients are denied real choice either because doctors do not present all available options or because they present options in such a way that patients are guided to the doctors' preferences. The extent to which choice is denied has been an area of debate, with different studies producing different results on what patients were told, whether it was what they wanted or needed to know, and whether they were satisfied with the information received (16;24;38;47;79;91;92).

WILL PATIENT INVOLVEMENT REDUCE PRACTICE VARIATION?

This leads to the thorny question of what would happen if patient views were better incorporated into decisions regarding discretionary procedures, particularly whether they would reduce variation. The idea that patient involvement will reduce variation rests on studies showing that patient acceptance of certain procedures was reduced by a combination of education and participation. Patients with prostate cancer who viewed an interactive educational video were more likely than control subjects to decide against screening and, where cancer was found, to prefer no active treatment (27). The same was true of patients with herniated disks, whose enthusiasm for back surgery was reduced after watching an interactive video (18). A Swiss population sample reduced its willingness to accept screening tests for pancreatic cancer after exposure to evidence on expected benefits and adverse events (20). In each of these cases, variation was reduced by limiting cases of high utilization.

These changes followed active patient education and occurred in areas of medicine where the benefits to patients of aggressive treatment are widely questioned. With other diagnoses and without education, patient preferences may not be so malleable. Beaulieu et al. (6) report that patients interviewed in focus groups in Canada resisted the recommendations of the Canadian Task Force on Preventive Health Care for elimination of routine exams and many screening tests. Patients in this study valued the information provided even if it did not affect outcome. Also, they were suspicious of science and of application of statistics to individual cases.

Breast cancer surgery is another case where the effects of information may be unpredictable. Apparently by extension from their prostate research, Wennberg et al. (88) hypothesize that "Wide variations in breast cancer surgical rates suggest that physician rather than patient preferences are the deciding factors in most cases." To accept this hypothesis, we must assume that doctors overprescribe mastectomies to patients who would otherwise choose breast conservation. The expectation that patient involvement will narrow variation also requires the counterintuitive assumption that surgeons are more diverse in their preferences than are patients, despite a shared training and socialization that has no parallel among the patient population. Data for this hypothesis do not yet exist.

THE CASE OF BREAST-CONSERVING SURGERY

Breast-conserving surgery (BCS) with radiation emerged in the mid-1980s as a serious challenge to the accepted modified radical mastectomy (MRM) after trials showed BCS to produce equivalent survival. In BCS the surgeon removes only the tumor rather than the entire breast. BCS was advanced as preferable to MRM because it was less mutilating (50;76;86). It has drawbacks, however, that may affect patient preference for it. With BCS, removal of the tumor is followed by 6 weeks of daily radiation therapy to catch stray cancer cells that may remain in the breast. Also, with BCS there is a somewhat higher risk of cancer recurrence that, if it occurs, requires a salvage mastectomy.

To explain continued variation in performance of the two procedures, scholars have examined a number of characteristics of surgeons and the medical environment. These include age of surgeon and size of hospital (19, 47), size of medical practice and physician involvement in up-to-date professional networks (57), attitudes of doctors toward multispecialty cooperation (necessary to BCS) (84), attitudes of doctors toward patient participation in treatment choice (26;38;54;56;66;79), and level of payment for BCS (56). Social characteristics of patients have also been studied, with researchers emphasizing socioeconomic level, age, and insurance (1;3;19;25;28;49;59;62;63;74).

Overall, studies suggest that younger, better educated, more professionally active physicians serving younger, better educated, better insured patients lead the way in adopting BCS. Older, more isolated physicians serving less privileged and articulate patients fall behind. Additionally, in the United States, adoption of BCS has been faster on the coasts than in the heartland. The presumption of most investigations appears to be that well informed and properly motivated physicians will prefer BCS and that patients who have information and are given a choice also will prefer this option. A decrease in variation is expected to result from declining use of mastectomy.

Caution is needed, however. Different surgical procedures reveal extremely diverse patterns of variation (88). Easy stereotypes of aging physicians in small towns of the American hinterland run afoul of the fact that, depending on treatment, extremely complex variations are observed. In the United States, practice variations may distinguish one small medical group from another or encompass large regions. An area's aggressiveness in one aspect of medicine is not necessarily accompanied by aggressiveness in another. An area that is innovative in one procedure lags in performance of another.

Not only do patterns vary widely by procedure, but also the more fashionable alternatives do not always show superior results. BCS is a case in point. Studies that examine the geographic distribution of cancer mortality in relation to levels of BCS find the Northeast to score high on both (high BCS and high mortality), possibly because of failure on the part of doctors or patients to fulfill the radiation component of the BCS protocol (22;31). Nor has evidence favored the inherent psychological advantage claimed for BCS. A controlled trial that examined adverse psychological consequences of breast surgery among women who were randomly assigned to the two surgical groups did not confirm higher rates of anxiety or depression among women who received mastectomies (33%) compared with those who received BCS with radiation (38%) (23).

THE NIH CONSENSUS DEVELOPMENT CONFERENCE ON EARLY STAGE BREAST CANCER

The recommendation of the 1990 National Institutes of Health (NIH) consensus conference on the treatment of patients with early stage breast cancer (65) was consistent with the pro-BCS bias seen in the literature. The panel endorsed BCS as normally preferable, saying:

Breast conservation treatment is an appropriate method of primary therapy for the majority of women with Stage I and Stage II breast cancer and is preferable because it provides survival equivalent to total mastectomy and axillary dissection while preserving the breast.

The NIH consensus identified certain factors that might in some cases indicate a choice of MRM. These were “logistic and emotional considerations, personal financial issues, and proximity and access to appropriate medical care.” Except for undefined “emotional” considerations, factors supporting a choice of MRM are actually obstacles that reduce access to BCS (logistic problems, financial problems, proximity). Possible lifestyle or value differences that might affect choice were neglected. Nonetheless, the NIH statement quickly became a standard against which practice was evaluated. Since its publication, numerous studies have measured doctor performance against it (1;19;38;47;49;50;51;52;62;66;79).

PERSISTENT VARIATION IN PROCEDURE CHOICE

Slow increases in utilization of BCS since 1985 have pushed it over the 50% level nationally, but levels of local utilization continue to vary widely, as does the application of the procedure for women in different demographic categories. These variations are not narrowing (21;22;28;38;49;63;88). In some localities rates of BCS are four times higher than in others. We seem to have reached dead-ends in bringing practice toward the NIH consensus recommendation and in explaining why BCS expansion has stalled. The usual explanations, lack of doctor knowledge and failure of doctors to involve patients in treatment choice, do not offer very much help.

Doctor Knowledge

Assessments of doctor knowledge of the scientific literature and consensus recommendations reveal them to be frustratingly well informed. In our research into the decision making of 50 surgeons, all surgeons provided acceptable estimates of local cancer recurrence rate for MRM (5%) and BCS (6%–19%) (40). Of those doctors who volunteered a patient survival rate (20 surgeons), all stated correctly that BCS and MRM were equivalent. These responses are consistent with more comprehensive research into physician knowledge (54;55;83;90). For example, Deber and Thompson (17), summarize their findings into the knowledge base of doctors who preferred BCS and MRM as follows:

The two groups’ assessments of clinical reality did not differ, their estimations of the probability of five-year survival, ten-year survival, and cure were virtually identical. The groups were similar in their acknowledgment of the value of clinical trials, saw themselves as research oriented. . . and gave almost identical responses to “I have enrolled patients in clinical trials.”

Provision of Information to Patients

Failure of doctors to alert patients to the availability of BCS also fails to explain the persistence of MRM. Guadagnoli et al. (38) surveyed patients at randomly chosen hospitals in two states marked by low and high levels of BCS. They reported that while some patients in Minnesota, a state of low BCS utilization, say they were not informed of the BCS option by their surgeons, this was insufficient to explain variation in treatment. They observe that “even if all of the women in Minnesota who underwent mastectomy and who said that their surgeon did not mention breast-conserving surgery underwent breast-conserving surgery, the increase (<2%) in the rate of breast-conserving surgery in Minnesota would not result in a rate that approaches the rate in Massachusetts.” (38)

Indirect Influence of Doctor on Patient Choice

Evidence for the indirect influence of surgeons on patient choices is also unpersuasive. Kotwall et al. (47) inferred an overweening doctor influence from data showing that 77% of patients at a university medical center identified their surgeons as their most important source of information. This is not an ideal measure of influence. A woman might well consider the most important “information” to be that which defined her medical situation and her treatment options. Given the bias in the question, what may be surprising is that 23% of patients identified some other source of information as more important than the surgeon.

A more direct question was asked by Stafford et al. (79), who surveyed all breast surgery recipients in the state of North Dakota. In response to the question “Who influenced your [treatment] decision?,” a majority of women (51%) identified their surgeon as the most influential person. Yet almost as many, 44%, identified someone else. Most prominent were family and friends (29%) and personal physicians (15%). Twenty-seven per cent (27%) indicated that they had been “significantly influenced” by someone else who had had cancer. This research suggests that women’s decisions reflect a number of reference points.

NEGLECTED INFLUENCES: FAMILY AND COMMUNITY

While there is relatively little attention to social context in the practice variation literature, there is other literature that points to its potential importance. From the literature on patient compliance, we do not learn what patients were told by their doctors or what they told them. We do learn that many patients ignore the doctor’s instructions after leaving the office. Especially notable in relation to our topic is research conducted by a team of researchers at the University of Wisconsin-Madison who studied patient compliance with recommended cancer prevention activities (colorectal, breast and cervical cancer screening, and counseling about smoking). Data were collected from 2,800 patients of 166 physicians practicing in 45 group practices. This research is particularly important because it tested simultaneously the effect of physician level, practice level, and patient level variables. Of all the variables related to physicians and practices (physician demographics, structure of practice, composition of clinic staff, payer mix, and so forth), only the physician’s recommendation to the patient was a significant predictor of whether the patient would engage in the target activities. However, while the physician’s recommendation was a significant predictor of patient behavior, it was overwhelmed in ability to explain variance by patient level variables, including social and economic factors, social norms, and patient perception of the health consequences of compliance (8;55). Other researchers also have identified the opinion of those in one’s social group as the most important factor in compliance with screening recommendations (5;43;44;60).

Studies of patient compliance with prescribed drug regimens report compliance rates between 25%–60% and even as low as 10% (15;61;72). Researchers fail to find explanation for low compliance in patient knowledge or in clinical issues (except number of daily pills). Across many studies, only ethnicity and race loom large as predictors. Based on a review of this literature, Ryan (72) urges more attention be paid to patient values and beliefs and to the means of coping that individuals learn in their life situations and from significant others.

Studies of compliance with other regimens show poor compliance to arise from a variety of culturally conditioned fears and attitudes, including fear of findings, anticipations of pain, perceived inability to pay, and embarrassment (4;11;12;48;53;69). Social integration is itself shown to influence compliance: Bruhn (9) reports that cardiac screening compliance is higher among members of large families, those having dependents, and those having longer tenure in the community. Kane and Kane (42) have attributed the difficulty that adult day care

programs have in maintaining client loads to practical problems like transportation as well as to patient resistance stemming from patients' desire for privacy and for personal choice of companions. Stewart et al. (81) have proposed that poor medical outcomes documented for patients in minority and lower socioeconomic groups may be explained by failure to adapt care to these patients' cultural beliefs about illness and treatment and the impact of treatment on work capacity and family roles. All of these studies point to family and community life as factors shaping willingness of patients to accept and fulfill treatment regimens.

Diversity of Health Beliefs Among Ethnic Groups

If we accept that group membership is the basis for learned attitudes and beliefs (including those concerning health and medicine), we expect the views of ethnic and other social groups to have characteristic attitudes. This is confirmed in the literature. Goodwin et al. (30) found that black, Hispanic, and white elderly subjects varied in their levels of fatalism about the cause of disease and in nihilism about its treatment. Receipt of preventive services was lower when symptoms were seen as a normal part of aging (fatalism). Subjects who felt that nothing could be done to treat their symptoms (nihilism) were less likely to have a regular physician. Similarly, Strain (82) found that patient attribution of chronic symptoms to social, psychological, or natural causes (work, stress, aging) influenced whether medical treatment was preferred over home remedies or other responses, such as altering one's lifestyle. Other studies confirm that individual assessments of illness and the appropriate response to it reflect cultural and social class beliefs and even linguistic categories of membership groups (2;46;64;82;96). Such differences are not captured in the crude social indicators that are commonly used in studies of health care access, as Yedidia (94) has shown in his study of the different actual experiences of patients despite health insurance coverage.

Diffusion of Innovation

Our perspective on the potential influence of family and community is influenced by studies of diffusion of innovation. These studies find that many innovations stall because potential adopters judge that an innovation does not fit with local circumstances or values and therefore judge that "it will not work *here*" (13;70;71). Concerns of physician adopters range from perceived inability of colleagues and the local environment to fulfill the obligations of a new technology (skills, facilities) to the cultural and social acceptability of techniques, including the likelihood of colleague and patient cooperation (33;34;35;36).

Physicians report being influenced in their treatment goals by perceptions of patient reluctance or patient rejection of options (95). Our team's research on breast surgery choice also found that surgeons' surgical recommendations to patients associated significantly with the concerns identified by their patients in separate interviews. Women who were very concerned about losing a breast were significantly more likely to receive a recommendation of BCS than were women who were concerned about fear of dying, fear of radiation, or who wanted to avoid the possibility of a second surgery. The association of surgeon recommendation with patient concerns occurred irrespective of individual surgeons' propensity to BCS or MRM determined by their responses to a clinical vignette (93).

SURGEON VIEWS OF PATIENT VALUES

Our interest in the extent to which surgeons incorporate patient concerns into their recommendations to them was not the initial focus of our research. Rather, similar to other doctor-focused studies, we had sought to identify surgeon characteristics that would explain

the slow diffusion of the 1990 NIH Consensus Conference recommendation favoring BCS. Our research site, southeast Texas, was an area where MRM was performed twice as often as BCS (88). At the time of our research in 1996, this corresponded to the median for the United States but lagged badly behind the NIH goal.

Against this initial framework, the data collected from patients were eye-catching. Among the 137 elderly women we interviewed, only 29% said that losing a breast was “very important” to them. Conversely 69% indicated it was very important to them to avoid the possibility of another surgery, 55% cited as very important a fear of cancer returning, and 40% indicated it was very important to them to avoid possible side effects of radiation (93). These findings are consistent with data presented by other researchers, showing that a significant number of breast cancer patients report concern over cancer recurrence, fear of radiation, a desire to shorten time in medical treatment, and a desire to avoid interventions (like radiation therapy) that make them dependent on others (1;47;79).

We conducted personal interviews with the 50 community surgeons who cared for the cancer patients in our sample. These surgeons volunteered comments that anchored patient views in culture and lifestyle and pointed to influential persons other than themselves. The following is a sample of the comments that intrigued us. Among the more striking comments were those relating to radiation, where surgeons’ comments suggested a struggle with patients who harbored what they considered to be misinformation. The following are some examples:

Most of them have had relatives or friends who have had radiation therapy for something else altogether, usually, and had a miserable time, or they have seen it on TV. They think that radiation therapy is going to make them very ill, and that they are going to be miserable. (#512)

Well probably [patients] are seeing other patients. They’ve seen the results of one of the others, and that may have been good or bad, in the others. Or [they have] horror stories that they’ve just been told by one of the others. They may have some misconceptions. . . . Everybody has a patient horror story where someone died from this or their skin was so burned from this. They may not have absolutely seen [this] but they just heard it from talking amongst themselves. (#4)

I would like to add that a good reason why most of them choose mastectomy is they are afraid of radiation. . . . The majority of them are afraid of radiation. It doesn’t matter how much you tell them that is not going to be a horrible thing. . . . I think they are afraid of several things. First of all, a lot of women in the elderly population had friends who were radiated 30 or 40 years ago, who had horrible experience with radiation. And it doesn’t matter how much [I tell them] the equipment is better. That is what is in their mind. (#543)

The doctors’ frustration in these cases may be relatively mild because two effective treatments are available. This is not always the case. Drawing examples from other areas of medicine, William Silverman observes that doctors face many situations “when those whose lives and well-being are at-risk, make crucial choices that seem to be patently unsound from their physicians point of view” (78, 126).

Surgeons also referred to the effect of their patients’ breast surgery choices on occupational and social obligations:

. . . they just want the thing off. They want to get better quickly. . . . They don’t care about dying. They care about loss of independence. What they are more worried about is. . . are they going to be able to get around. Because we are in a rural community here, and people have to be able, are they going to be able to drive—that is a big question. Are they going to be able to get up and cook their dinner meal and use their arm right after surgery? . . . See the people down here, a lot of these are widows, their husbands were rice farmers, they have big farms. They have animals to feed. They have things to do. They are very involved in their church. They are babysitting grandkids. That kind of thing. They are a different group. (#29)

[With radiation] . . . they feel like they're bothering someone. They feel like they're putting a family member out, they're breaking, interfering in someone else's ability to work or take care of their children. Or they have to ask a neighbor. They don't like imposing. (#5)

. . . They don't want time taken out of their lives, out of the day to day routine going for radiation. They will tell you "Baby, I don't want to do that every day. I'm not taking the time to do that. . . ." And some will say, "Well I play the piano at church. I don't have time to go for radiation. I need to get things done." They'll ask you: "If I have a breast taken off, do I have to have radiation? No? Well, that is what I want. . . . I have to take care of my grandchildren. I got to be able to pick up my grandbaby. I don't want my grandbaby not to be able to hug me and kiss me. (#9)

One doctor speculated specifically about the culture of the particular region:

There are lots of women who are very sort of matter-of-fact. "Oh just take the whole thing off. I don't need to worry over it." I find that from a general self-image thing that there is a difference with an older person. At least in my experience with the people I work with. . . . I don't know if this is only Texan because I wonder if I would find it everywhere else. But you know, this sort of matter-of-fact down-to-earth Texan who just sort of says: "Oh go ahead and take that off. . . ." I don't think that is necessarily everywhere, but I seem to see a lot of it here. They're fun. These people are straight. They say what they think. (#7776)

In sum, doctors often referred to the social context of patients in their practices, citing patients' concerns and relating these to information they receive from family and friends and to their social obligations and cultural preferences.

We do not suggest that factors affecting patient attitudes and behaviors should replace study of factors affecting doctors, but rather that the best research premise might be that there is a process shaping the views and behavior of doctors, a process shaping the views and behavior of patients, and an interaction between the two.

DIVERGENCE FROM RECOMMENDED PRACTICE

There were troubling statements by surgeons in our Texas sample who felt that they were unfairly criticized for high rates of mastectomy. One described it this way:

It is always interesting in the meetings . . . The northern and the eastern group are always on the southern group for having such a high percentage of mastectomies. . . that we are biased in our presentation. . . But I really don't find that is true. I have been just as fair as I can be to present these things to the people. Folks just select. They just pick the mastectomy. . . (#270)

Said another:

It is one thing to sit there and say, "Oh, this is the way it should be done," and when you sit there and talk to patients, they have prejudices against the way things are done. And the patients don't always fit into, like a round peg into a square hole. (#46)

Said a third:

I have a problem with the meetings I go to. The guys will stand up there and say it is criminal to cut the breast off. You know, we have got to consider these women. They are NOT NOT considering this human being [who] may not want radiation. O.K? [Some patients] feel very awful to watch that [remaining] breast tissue [while] I am off conserving the breast. ONLY ONLY if that is what the patients feel comfortable with and want. You cannot impose [your] values on other people. . . You have to really sit down and take your time and get into the psyche of this patient and see what they feel. You can't make them feel stupid because they want a mastectomy. (#44)

THE POTENTIAL CONFLICT OF GUIDELINES AND PATIENT VALUES

If there is a serious possibility that clinical practice reflects patient preferences and the willingness and capacity of patients to accept or fulfill treatment options, the nature and use of guidelines become complex. Certainly there is a danger of blaming the victim—the patient for her values, the doctor for her patients. And there is danger of introducing value choices under the guise of preferred practice. The NIH consensus panel overstepped data in assuming that patients preferred BCS except under very limited conditions. If a value such as preserving the breast were to be a topic of NIH consensus discussion, the discussion would have benefited from data on the distribution of this value in the population. That there was no evidence for the universality of the value embraced should not have escaped a panel assembled to improve the evidential basis of medicine.

The NIH Conference may be an exception. The 1998 Canadian Consensus Statement on the Care and Treatment of Breast Cancer (80) took a far more balanced view than the U.S. statement. It also stated that BCS was “generally recommended,” but the statement carefully specified tradeoffs for the patient and advised that “the choice between BCS and mastectomy can be made according to the patient’s circumstances and personal preferences.” Canadian and European healthcare systems seem more often to postulate community differences. Diversity among communities is an implicit assumption in a number of health initiatives in Europe and Canada. An example is the Finnish Prioritization in Health Care Project (45;73). We see less recognition of community differences in the United States, although the aggressive marketing of prescription drugs to patients suggests that at least drug companies believe patients to be influential in treatment choice. Insurance companies also seek to influence the patient as a means to influence the doctor.

IMPLICATIONS FOR RESEARCH AND POLICY

In light of the many studies that demonstrate the importance of culture to health beliefs, behaviors, and compliance, it is a plausible hypothesis that these differences make their way into the practices of local physicians. While the preferences and roles of patients in different geographic communities cannot presently be linked to treatment patterns, it is likely that preferences are geographically patterned in relation to an area’s socioeconomic status, age of population, ethnicity, local culture, and lifestyle.

Directions for Research

We suggest heuristic suspension of the prevailing assumption that doctors determine medical treatment with minimal influence of patients. We should make patient roles a subject of empirical inquiry rather than speculation. Two broad hypotheses emerge. The first postulates that doctors in different practice areas face patients who live in particular social situations, are influenced by information available in their communities, and have cultural beliefs that affect medical preferences. To assess the existence and magnitude of these differences, research is needed in at least these areas: patient beliefs about different medical situations and available interventions, patient sources of information and influence, and cultural roots of medical care preferences. The second broad hypothesis postulates that there are mechanisms by which these patient and community variables enter medical treatment decisions. To begin, we might premise either that patients tell the doctor what they want or will accept or, alternatively, that doctors believe that they know this.

More Humble Guidelines

In practice guidelines, *a priori* assumptions about patient values should be avoided. Guidelines should recognize when values are at stake, seek pertinent evidence, and, short of

attaining it, be respectful of the potential for patient values to be quite different from one community to the next and at variance with those of the experts. Focusing on doctors as the cause of variation at the expense of investigation into patient roles may obscure a potentially important tension between practice geared to guidelines and practice geared to patients. As we seek to narrow medical practice variation *and* to enhance the rights of patients to a treatment of their choosing, we must ponder the possibility that these goals could be in conflict.

Social Context of Medical Practice

Until we better understand practice variations, we are unable to persuasively criticize, defend, or suggest alterations to them. When baseline information becomes available, we may then debate its implications. Iain Chalmers (10) posed the challenge hypothetically in a 1983 article. He proposed 20 influences that bear on medical decisions ranging from need to commercial interests. His listing, he has said, indicates his rough ranking of the defensibility of different factors. No one has been more concerned than Chalmers has been with the need for patients, clinicians, and policy makers to pay attention to relevant, valid research evidence. Nonetheless, in his rough ranking, he placed scientific evidence fifth after need and three factors that orient the doctor to the patient (personal communication, 2001). Higher-ranking factors included culture, clinical experience, and client experience. The doctor that emerges is one who practices scientific medicine in a social setting.

It has not been the purpose of this essay to characterize either the process of treatment decision making or the preferences of patients. Rather, we suggest that these things need to become known. In addition to the values of patients, families, and communities, we believe treatment decisions will reflect the professional, social, and financial characteristics of local areas. Efforts to change practice have far exceeded available data in assuming the controlling role of doctors in treatment choice. Documentation that practice variations exist by locale rather than by individual physician should have been, and should now be, an impetus to empirically investigate all plausible factors that clump by geography and in the practices of physicians. We need to consider the array of factors that may impinge on treatment decisions and the mechanisms through which they work. We have neglected the most fundamental question of all: why do practice variations exist? Only when we have a better answer to this question can we debate which attitudes and behaviors should be subject to education and which should be objects of respect. "Clinical experience" of what patients prefer may not be a recommended guide to best practice but, in order to improve on clinical judgment, national advice must be humble and research must present stronger evidence, not weaker.

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