

SHOULD PATIENTS HAVE CONTROL OVER THEIR OWN HEALTH CARE?: EMPIRICAL EVIDENCE AND RESEARCH ISSUES

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ABSTRACT

Available research indicates that purported patient insufficiencies in ability to process information and make rational and reliable decisions have likely been overestimated. Furthermore, data indicate that nonscientific factors often play a role in physician decision-making and that physicians may not value different health outcomes in the same way as patients. Though the data on patient cognitive functioning are limited because of heavy reliance on patient responses in hypothetical versus actual decision-making situations, these findings lend credence to arguments that patients should have increased control over their own health care. Research on the effects of interventions designed to enhance patient control indicates that: (a) patients generally respond positively to increased information, but few studies have evaluated the effects of information as a precursor to decision-making; (b) the few studies using simple behavioral control interventions have shown generally positive effects on a range of patient outcomes; and (c) studies of decisional control (with breast cancer patients) have had experimental confounds which prohibit conclusions regarding effectiveness. Areas in greatest need of research include: (a) further exploration of the utility of noninvasive behavioral control interventions in different settings; (b) measuring the impact of control manipulations on patient perception of control as well as patient control-related behaviors; (c) matching patient differences in desire for control to experimental conditions and to physician differences in receptiveness to patient control; and (d) clinical trials in which patients facing critical decisions in trade-off situations are actually given a choice.

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INTRODUCTION

Health care professionals and laypersons agree that it is desirable for patients to actively participate in their own health care (1–6). Increasing patient autonomy is said to not only be congruent with legal mandates, but also ethically correct in terms of adjusting the power asymmetry between doctors and patients. Furthermore, based on findings with both animals and humans of largely positive effects of having control and negative effects of loss of control in aversive situations (7,8), there is reason to believe that increasing patients' involvement will positively affect their emotional adjustment, quality of life, and perhaps even survival and mortality (see 9). However, available data indicate that patients continue to play a largely "passive role" in interacting with their physicians (10–12), and that many working physicians continue to be reluctant to cede responsibility to patients (13–16) and in fact make minimal efforts

to foster patient decision-making involvement in day-to-day office practice (17).

Reservations about giving patients a more active and collaborative role with their physicians have focused on three major areas. These include the questions of whether: (a) patients actually want to become more involved in their own care; (b) there are patient limitations in cognitive capacity, objectivity, and ability to process information that might preclude their meaningful participation in decision-making and self-care activities; and (c) patients actually benefit from attempts to give them more responsibility and control. The first area has been the subject of several recent reviews (18–20). It has been concluded that, in general, patients want involvement to the extent that they think it will increase their chances of a positive medical outcome. There are patient differences in the extent to which they want control, but the self-report measures on which these conclusions are largely based have been insufficiently validated to be used as predictors of how patients will respond when given opportunities for control (18). The present review focuses on the latter two areas. The second area is broadened to the more general issue of the overall rationale for increasing patient involvement. Thus, in addition to examining putative patient limitations that might preclude involvement, data regarding physicians' objectivity and ability to accurately represent patient values are also considered. In addressing whether patients benefit from increased control, research investigations are reviewed that have attempted to evaluate whether giving patients more control, in fact, enhances their health, satisfaction with care, and/or psychological adjustment.

IS THERE A STRONG RATIONALE FOR LIMITING PATIENT CONTROL?

Arguments that have been presented for limiting patient involvement in their own care include: (a) patients usually do not have the cognitive capacity or background for processing the information needed to make an informed decision (i.e. understanding risks and values associated with potential outcomes); (b) patients are not objective about their health status and thus cannot be expected to make rational decisions about treatment; and (c) patients are inconsistent and unreliable in making medical decisions. In addition to evaluating available evidence bearing on these viewpoints, data pertinent to the following assumptions regarding physicians as decision-makers will be considered: (a) physicians largely are objective decision-makers, and (b) physicians value different outcomes in the same way as do patients.

Patients Lack the Cognitive Capacity Requisite for Control

A widely-voiced concern is that because of lack of education, background, or basic intellectual ability, patients will be unable to understand and retain medical information sufficiently for them to participate in a fully informed fashion with their physicians.

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Evidence: Siminoff (21) in a 1989 review concluded that studies of cancer patients consistently found poor recall of information and understanding by them of their condition. More recent studies (3,22,23) have obtained data consistent with this conclusion. Similar findings have been obtained with general practice (24,25) and postsurgical (26–28) patients. But a difficulty in making firm generalizations from these findings is that in most studies it is unclear what patients were actually told or how specifically information was actually conveyed to them, or in what manner. This is significant because specificity of information presented (amount, clarity, gives explanations, etc.) is the best predictor of patient recall and understanding, and manner of information presentation (positive talk—use of humor, empathy, etc.) also has a positive impact on these variables (based on a meta-analysis; 29), as do physician nonverbal behaviors such as forward lean and direct body orientation (30; see 31) and the appearance of being calm and relaxed (32). In two studies in which the information actually given to patients was documented through audiotaping and in which patients did a poor job of retaining information pertaining to relative treatment risks or probability of survival, crucial information was rarely found to be presented in specific, numerical terms by the physician (33,34). Other recent findings indicate that cancer patients do not process disease-related information deemed by physicians to be objective and appropriate, because the patients do not consider the information to be personally relevant or responsive to their main concerns (35).

Recent research with “decision aids,” devices designed to clarify for patients what is at stake and what can be achieved as a result of treatment (see 36,37 for reviews), has shown that patient recall and comprehension are satisfactory and can be improved when special attention is paid to how information is presented. For example, Levine et al. (38) developed a decision board for use with cancer patients that visually provides detailed information on a patient’s treatment choices, the specific outcome probabilities in terms of recurrence, and the specific quality of life implications associated with each choice. Using this device, cancer patients’ comprehension of survival benefits associated with alternative treatments was found to increase significantly (39,40). In nonpatients, treatment preferences were highly stable over time when presented with the same risk/benefit ratio and shifted predictably when the magnitude of survival benefit and the toxicity of the treatment were changed (38–41). O’Connor et al. (42) found that a decision aid using a self-administered, self-paced booklet and audiotape produced less decisional conflict and more realistic expectations with respect to outcomes than a general educational pamphlet in postmenopausal women considering hormone therapy.

Another specialized presentation mode is interactive video-disk programs which present information in a variety of formats (e.g. in the form of interviews with patients who have experienced benefits/harms) and provide menu options for more information (see 43–45). Initial research indicates that exposure to this format significantly influenced decision-making in patients with benign enlargement of the prostate (BPH) (46) as well as in ischemic heart disease patients (47). In the latter group, although some patients reported increased anxiety, overall confidence in treatment decisions increased and preferences for alternatives declined.

Conclusions: Numerous studies indicate that information provided by physicians is often poorly assimilated by patients. However, recent research indicates that patients’ retention and ability to use information may be improved depending on specific-

ity and clarity of content, manner of delivery, and relevance to patients’ major concerns.

Patients Are Irrational and Unable to Make Objective Judgments of their Medical Condition

It has been asserted that patients’ accounts of their illness status are often unreliable, distorted by emotional distress, and only weakly correlated with objective measures of actual functional status (48), and that their beliefs are susceptible to biases and preferences and seem to be irrational (49). As a result, physicians must attend carefully to situations in which patients are making irrational choices that are contrary to their own well-being (50).

Evidence: In general, people often deviate considerably from rationality in making decisions. We are influenced by a number of biases. These include choosing an alternative that satisfies our most important needs rather than the one that has the highest overall utility; a tendency to be risk-averse when outcomes are framed positively and risk-seeking when they are framed negatively as predicted by prospect theory (51) (and other framing effects); plus hindsight bias and a tendency to reduce cognitive dissonance. All of these biases violate the assumptions that underlie rational decision-making (52). Research pertaining to medical decisions has particularly addressed framing effects. Most studies have used vignettes presenting hypothetical choices involving clinical problems to patients, leaving open the question of generalizability of findings to decision-making in actual clinical situations. With few exceptions (e.g. 53,54), however, most of these studies have shown the expected framing effects predicted by prospect theory (e.g. 55–57) as well as other framing effects (58,59). But these biased judgements are not exclusive to patients. In evaluating information and making decisions, physicians are influenced by many of the same subjective factors and biases (56,57,60–62).

Other research bears on the question of whether patient choices regarding information needs and treatments seem to be logically related to their medical condition or other aspects of their life situation. Studies in which patients responded to vignettes (hypothetical scenarios) depicting disease situations support the notion that, in general, patient preferences for information systematically and logically vary as a function of individual differences (and contextual factors). Studies with breast cancer patients (63,64) and prostate cancer patients (65) indicate that patients have specific hierarchies of informational needs (with information about likelihood of cure and spread of disease rated the highest) and that content of information desired is logically related to individual patient needs and situational factors. For example, information about sexuality and physical attractiveness is more important to younger (<50) versus older (>50) breast cancer patients (63,64); information about chances of cure is more important to breast cancer patients who want an active role in decision-making (63); and information about self-care is much more important to single versus married prostate cancer patients (65) and to older (>70) versus younger (<70) breast cancer patients (63).

Consistent with data on informational needs, available findings indicate that when faced with treatment decisions involving quality/quantity of life trade-offs, patients have distinct preferences that are usually related logically to individual differences and contextual variables. O’Connor (59) found that in cancer patients who were presented such decisions in the form of hypothetical treatment alternatives, preferences for toxic treatment were weaker to the point where chances of survival dropped below 50%. Stigglebout et al. (66), in a questionnaire study with cancer patients, found that younger patients and those with children

assigned more importance to prolonging survival than to enhancing quality of life. Similarly, Yellen and Cella (67), in a vignette study with a diverse group of cancer patients, found that having children living at home and a high level of social support predicted patients' willingness to accept more toxic aggressive treatment that would improve likelihood of 1-year survival rate. In another vignette study with cancer patients, Yellen et al. (68) found that younger patients were relatively more concerned with survival than quality of life; younger patients were willing to switch from a mild to a more toxic treatment to gain a survival advantage at an earlier point than older patients. McQuellon et al. (69) similarly found, in a scenario study, that younger breast cancer patients were more willing to accept a toxic treatment for a small increase in life expectancy. They also found that, as a group, patients were rational decision-makers—accepting toxic treatment only to the point where the perceived risks were outweighed by the potential increase in life span. Mazur and Merz (70) presented older male general medical patients a hypothetical situation in which a patient with localized prostate cancer was offered the treatment options of either surgery with a defined set of complications or expectant management ("watchful waiting") and found that patient preferences were consistent with their experiences and physical problems associated with prostate disease. Only one study of this type (71) found no clear logical relationship between patient preferences and patient individual difference data.

Conclusions: In general, studies do not support the assertion that patients are unable to make objective and rational assessments of their physical condition. There is evidence that patients weigh factors systematically when making judgments and that their preferences for information, as well as their treatment preferences when faced with quality/quantity of life trade-offs in hypothetical situations, tend to be logically related to their individual needs and to contextual factors.

Patients are Inconsistent and Unreliable in Decision-Making

Reliability has traditionally been evaluated from the standpoints of both internal consistency of judgments as well as their stability over time.

Evidence: Internal consistency has been evaluated in several studies in which patients have been faced with decisions that involve quality of life/quantity of life trade-offs. A reliable finding is that patients facing diseases with serious or potentially serious consequences are more concerned with survival relative to having to endure unpleasant side effects of treatment (53,69,72–75). All of these studies with one exception (74) evaluated actual patients, but of these all (except 73) involved the patients responding to hypothetical scenarios rather than actively confronting decisions immediately pertinent to their health status. Nonetheless, in each study the findings were predictable. Respondents were risk averse. On the average, they were unwilling to accept even a slightly increased risk of death in order to avoid side effects of toxic treatments.

Stability of patients' decisions over time has been evaluated in studies of: (a) cancer patients and (b) patients' choices regarding advance directives for life support in situations where they were rendered incompetent or otherwise unable to make decisions. The findings of these 12 studies (53,76–86) are summarized in Table 1. The findings of the studies with cancer patients are particularly significant. In four of the five studies (53,77–79), patients' decisions, which were directly relevant to their condition or

treatment received, remained stable over periods ranging between 1 and 3 months despite the interposition of treatments producing strong changes in quality of life. Among the seven studies involving advance directives, two reported significant test–retest changes among patients (85,86). But in each case there were data to indicate that patient changes were at least, in part, due to realistic considerations either involving re-evaluation of benefits and burdens of life-sustaining measures as death approached or changes in physical health, rather than whim or chance variations in response.

Conclusions: Available evidence supports the conclusion that patients are largely reliable in the medical decisions they make from one time to another. Moreover, patients seem to be internally consistent in their decision-making and in the relative weights they assign to treatment options and consequences.

The Physician Is an Objective Decision-Maker

A primary argument used by proponents of physician autonomy to justify minimizing patient involvement is that patients, for a range of reasons, are not capable of taking responsibility for logically processing information and making logical choices. In contrast, physicians are presumed to be objective decision-makers whose choices are based on scientific data and who are minimally affected by biases or subjective factors. Thus, physicians should choose for patients.

Evidence: As noted earlier, research findings suggest that in evaluating information and making decisions physicians are influenced by many of the same subjective factors and biases as are patients (56,57,60–62). For example, McNeil et al. (57) found (in a scenario study) that several framing factors (e.g. whether the problem was framed in terms of the probability of living rather than the probability of dying) significantly influenced patients' choice of treatment for lung cancer. However, this effect was just as strong for physicians (radiologists) and for business graduate students who had completed courses in statistics and decision theory. Perhaps more compelling are findings that physicians' real world decisions are associated with factors irrelevant to treatment effectiveness, such as their specialty training and/or geographical location (87–92) and may be more strongly influenced by these contextual factors than by knowledge of results of clinical trials (91,92). In the area of treatment of non-small cell lung cancer, for example, it has been concluded from surveys of practice variations that variations in use of radiation and chemotherapy are not influenced by differential patient survival (93). Canada survey data indicates that new knowledge produced in clinical trials has done little to alter physicians' beliefs or reduce practice variations (94). In general, the findings reveal that physicians are reluctant to change practices even when randomized trials demonstrate the effectiveness of a new treatment, and also that giving physicians feedback regarding how their practices or patient outcomes compare with others or with an external standard has had inconsistent (highly variable) effects in changing physician behavior (95, see 96–98). There is also evidence that in addition to biomedical factors, subjective values and social expectations and attitudes play a significant role in physicians' treatment choices (99). In one study with American physicians (100), the most important influence on physicians' choice of treatment for breast cancer was their attitude toward patient involvement in decision-making (willingness to involve patients was associated with preference for more conservative local excision and radiation

TABLE 1
Studies Evaluating Stability of Patient Decision-Making Over Time

Study	Subjects	Choices/Outcomes Assessed	Test-Retest Interval/ Intervening Treatment?	Results
Cancer Patients				
Brundage et al. (76)	56 (lung or prostate) cancer patients who had completed treatment (and 20 clinic staff); 11 patients and 9 staff were retested (unstated how they were selected)	Weighing of survival benefits vs. toxicities of different treatment options using scenario depicting Stage IIIB NSCLC patient just after diagnosis	6 weeks/No	Survival advantage thresholds at time 1 and 2 significantly correlated; most patients declared same treatment preference on both occasions
Cassileth et al. (77)	147 Stage D prostate cancer patients	Choice of surgical castration or hormonal treatment	3 months/Yes—patient given treatment of choice	93% of patients and 91% of patients' wives said they would again select the same treatment
Llewellyn-Thomas et al. (78)	50 laryngeal cancer patients	Assessment of values regarding different aspects of voice function	1 month/Yes—radiotherapy	No change, despite expected deterioration in voice-related symptoms and abilities
O'Connor et al. (53)	54 (mixed) cancer patients	Preferences for two hypothetical treatments differing in probability of survival and toxicity	6 weeks/Yes—chemotherapy; Patients had no choice in treatment	Preferences did not change in mean value and were significantly correlated despite experience of "significant toxicity" following treatment
Slevin et al. (79)	50 patients with newly diagnosed solid tumors (unstated how the 50 who were reevaluated were selected from the original sample of 100).	Willingness to undergo chemotherapy with toxic side effects vs. milder chemotherapy	3 months/Yes—one of the two chemotherapy treatments; unstated if patient could choose	No change in preference regardless of type of treatment actually undergone
Patient Choices Regarding Advance Directives for Life Support				
Beland and Froman (80)	116 healthy adults	Life support preferences as measured by a 6-item scale depicting vignettes of an incapacitated patient	2 weeks/No	85% average agreement in preferences over time
Danis et al. (81)	2,073 Medicare recipients receiving a broad range of outpatient care	Desire for life-sustaining treatments if they were to become terminally ill	2 years/No systematic treatment	Choice to forego treatment 2× as stable (85% no change) as choice to receive treatment
Emanuel et al. (82)	296 mostly primary care outpatients and 78 healthy adults; 154 of the patients completed a third evaluation	Advance directive choices assessed via scenario, and specific treatment choices	6–12 months; third evaluation at 12–24 months from first testing/No	Patients: Pooled agreement across 3 evaluations = 72% (1–2: 76%; 2–3: 80%). Nonpatients: 1–2: 69% agreement
Everhart and Pearlman (83)	30 intensive care unit patients	Preferences for life-sustaining treatments assessed for patients' current health situation and two hypothetical illness conditions	1 month/No	Preferences were stable (median kappa = .58) despite significant changes in health status and mood
Schneiderman et al. (84)	Initial sample: 104 patients with "life-threatening" disease	Preferences re: lifesaving treatments assessed as part of a proxy-instruction advance directive	1 year/No	None of 58 patients still alive changed their choice re: circumstances under which they wanted life prolonged (among 3 alternatives); no change in choice of specific procedures
Silverstein et al. (85)	Initial sample: 38 amyotrophic lateral sclerosis patients	Preference for CPR assessed via response to two hypothetical illness situations	6 months/No	11 patients and 5 patients (of 26 patients still alive and cooperating) changed their initial preference on the first and second scenarios, respectively
Weissman et al. (86)	252 AIDS patients	Desire for CPR; preference for life-extending treatment in hypothetical illness situations	4 months/No	Approximately 25% changed preference for life-sustaining care; patients reporting changes in physical function, pain, suicide ideation more likely to change

treatment versus radical mastectomy). The same association was obtained in a second study with Italian physicians (89).

Conclusions: Available evidence indicates that physician decision-making is not strictly determined by knowledge of clinical trial outcomes and is influenced, perhaps to a significant

degree in some situations, by contextual medical practice factors and general human biases.

Patient and Physician Share Common Values

To the extent that there is evidence that physicians' subjective decision priorities differ from those of patients, credence is lent to

the argument that there needs to be increased sharing of information with patients and involvement by them in decision-making.

Evidence: There is evidence that patients' priorities regarding the extent to which they value different outcomes often differ from those of physicians. As noted above, patients with serious chronic diseases have consistently been found to be willing to undergo highly toxic treatments in order to obtain even a small chance of enhancing survival. Slevin et al. (79) compared cancer patients' decision priorities with those of physicians and nurses, and found that this effect was much more pronounced among patients than among physicians or nurses, with both of the latter groups far less likely to accept radical treatment for minimal survival benefit. Significant gaps have also been observed between patients' preferences and their physicians' assessment of their preferences for life-sustaining procedures such as cardiopulmonary resuscitation (24,101–106) and other medical procedures (107). In one study (105), physicians were no more accurate than nurses (both failed to exceed chance levels of agreement with patients in most decisions) and did not significantly agree with each other. In another study (106), attending physicians were no more accurate in assessing patients' preferences than were medical interns, despite having had significantly more extensive contact with the patients than the interns. Alpert and Emmanuel (108) examined actual life-sustaining treatment decisions made by medical staff and found that treatments received by patients did not conform well (range = 44%–72% agreement) to patients' specific preferences. Other research in situations involving risk/benefit trade-offs has documented significant physician–patient differences in utilities for clinical outcomes, leading to differing physician–patient choices of amniocentesis versus chorionic villus sampling for prenatal genetic testing (109) and surgery versus radiotherapy for treatment of colorectal cancer (110).

Conclusions: These findings call into question whether physicians view outcomes in the same way as patients and the ability of physicians to accurately represent patient values in choosing treatments.

HOW DO PATIENTS RESPOND WHEN THEY ARE GIVEN CONTROL?

As noted earlier, research in a variety of settings has generally found assumption of control (or the perception thereof) to be associated with superior ability to deal with aversive situations and loss of control to be detrimental. Studies specific to the medical setting examining the relation between patients' self-reported adjustment to their illness and either their post hoc self-report of perception of control over their illness (e.g. 111,112), their degree of interaction with their physician (e.g. 113), or their decision regarding choice of treatment (e.g. 114) have similarly generally showed patient perceptions of control to be associated with better adjustment (see 115); in cancer patients, low perceived control has been found to be a strong predictor of first recurrence and death from the disease (116). But these findings have been based on correlational designs, and laboratory studies indicate that positive outcomes may lead to retrospective perceptions of control (see 117). Thus, this research does not directly address the question of how patients respond to conditions or treatments that actually offer different degrees of control or to manipulations designed to enhance their sense of control.

Research in which control has been manipulated or otherwise examined as an independent variable in the health care setting is reviewed in this section. In conceptualizing these studies, patient control will be considered in terms of the three generally recognized major ways that people can exercise personal control in aversive situations: cognitive/informational control, decisional control, and behavioral control (7,8). Cognitive control involves processing information that, by reducing ambiguity, results in situation reappraisal that reduces perceived threat and fosters a sense of control. The less presumptive term "informational control" will be used herein because researchers rarely independently assess how delivered information is processed by patients. Exercise of decisional control goes beyond relatively passive information processing. As used in this paper, it involves formulation of preferences and participation in choice of available diagnostic or treatment procedures associated with established outcomes, but does not include technical problem-solving on the part of the patient (see 118). Behavioral control refers to direct action on the environment. It usually presumes some level of decisional control plus some degree of patient autonomy in the implementation of treatment or diagnostic procedures.

Informational Control

Proponents of informed consent argue that full disclosure of medical information facilitates patient participation in decision-making and by fostering a sense of control lowers patients' stress and enhances their adjustment. An alternative view is that confronting patients directly with the facts of their situation strips them of protective cognitive defenses, thereby increasing their stress level (e.g. 119,120) and inhibiting their ability to process information and participate meaningfully in management decisions (e.g. 121–123); this is a plausible concern given laboratory findings that memory capacity and other aspects of cognitive functioning show decrements in high-threat situations especially with complex tasks where sustained attention is required (124).

Evidence: Numerous studies have evaluated the effects of "psychoeducational" interventions or informational programs on patient stress and other adjustment-related outcomes. Different parts of this literature have been reviewed relatively recently by several authors (e.g. 21,125–128). Some portion of otherwise healthy patients facing transitory procedures (126) as well as cancer patients (e.g. 129,130) have reported increased stress after exposure to detailed information. Overall reported effects of informational interventions, however, are positive. Suls and Wan (128), in a meta-analysis of studies of the effects of providing preparatory information to patients facing stressful medical procedures and pain, found strong and consistent benefits in reduction of negative affect, pain, and other-rated distress when a combination of sensory and procedural information is given. Simonoff (21) concluded, in a descriptive review, that most studies with cancer patients have found information disclosure to have largely positive effects, including decreases in emotional distress. Meyer and Mark (127) in a meta-analytic review of randomized control–outcome studies with cancer patients concluded that informational interventions produce a significantly positive but small effect size on patient outcomes of behavioral, emotional, and physiological status or medical state, with several studies (e.g. 131–134) reporting decreases in patient anxiety, though some of these studies involved multiple-component treatment packages in which education was combined with interventions such as diet and relaxation (e.g. 135,136). Other research with cancer patients has shown that information provision produces enhanced recall of treatment risks

and benefits (129,130,137,138) and significantly influences patients' decision-making regarding treatment preferences using a scenario format with a decision aid (39–41,43–46).

Conclusions: Enhanced information provision has positive effects on a wide range of patient adjustment-related outcomes. However, the mediating mechanism by which information produces these effects—whether it elicits an increased sense of control over potentially aversive outcomes (or even a sense of participation or involvement)—is almost never evaluated. Furthermore, very few studies, either with healthy patients facing circumscribed diagnostic or treatment procedures or with chronic disease patients, evaluate response to information as a precursor of involving them in decision-making. Almost all studies with the former group have examined the palliative effects of information in easing emotional distress in patients prior to their submitting to procedures that have already been agreed to. The few studies that have examined information provision in conjunction with both patients' measured stress level and their subsequent participation in decision-making (47,132) have found no evidence of patient anxiety inhibiting decision-making, and recent studies with decision aids indicate positive patient response in hypothetical situations. But, overall, the concern of some physicians that exposure to bad news in pivotal decision-making situations will increase some patients' emotional distress and impair their ability to meaningfully participate has not been adequately researched.

Decisional and Behavioral Control

There has been increasing emphasis on the need for patients not only to be fully informed but also to participate in decision-making and aspects of self care. Some "patient-centered" models of health care even advocate independent decision-making by patients (139; see 4). But, given the physician–patient differential in skill, knowledge, and experience, many physicians (especially those who are highly trained) understandably remain skeptical about the utility of active involvement by patients (14).

Evidence: The effectiveness of conditions designed to give patients increased decisional or behavioral control or influence their perception of same has been evaluated in a small number of studies. They are divided into four groups: (a) studies in which patients were instructed and explicitly encouraged to take an active and assertive role in interacting with their physician (Group 1), (b) studies in which hospitalized patients were given interventions designed to influence their perception of control over their treatment environment (Group 2), (c) studies comparing patients' response to treatments thought to differ in the amount of behavioral control afforded patients (Group 3), and (d) studies with breast cancer patients designed to evaluate whether giving patients choice of treatment versus no choice produces superior adjustment (Group 4). Excluded from consideration are studies in which there was no explicit intervention or set of stimulus conditions designed to produce increased patient control (e.g. 140–142), those in which control interventions were not evaluated as a main effect (143,144), and those in which experimental conditions were not sufficiently operationalized or clearly designed to produce patient changes in control (145,146).

The design and outcomes of studies meeting selection criteria (12,147–163) are summarized in Table 2. In each case, assignment of subjects to conditions was random unless otherwise noted. Independent verification that conditions designed to increase patient exercise of control or perception of control in fact did so was obtained in only four studies (12,147,148,150). In the three

studies in Group 1, patients were given extensive training in how to use information in order to take a more active role in understanding management issues and in decision-making. In each case independent data were obtained, via coding of audiotapes of physician–patient interactions, that patients given the experimental interventions, in fact, took a more active role. In the two Greenfield et al. studies (12,147), exposure to the experimental intervention resulted in better outcomes on a range of measures, whereas no differences were reported in the Rost et al. study (148).

Common to the interventions employed in the three studies in Group 2 was the opportunity given to experimental patients to exercise behavioral control in ways that were peripheral to their medical care. Cromwell et al. (149) came closest to involving some patients in medical care-related activities by encouraging patients in their "high participation" condition to activate their own cardiac monitors to secure an electrocardiogram (ECG) tracing when they felt a symptom (the tracing was subsequently given to the patient's physician). In all three studies, the experimental interventions produced superior outcomes, though in Cromwell et al.'s three-way factorial design (there was no no-treatment control group) only patients receiving detailed information in conjunction with either high participation or high diversion (which included control over visitation) had improved outcomes.

The studies in Group 3 are based on the assumption that different degrees of patient control are inherent in different kinds of treatments. One set of these studies addressed the question of whether direct provision of behavioral control over pain reduces the experience of pain for patients. Patient-controlled analgesia (PCA) devices consist of infusion pumps that allow patients to self-administer analgesic medication and program variables such as dose, time between doses, and maximum dose per time period. In a meta-analysis of 15 studies of postoperative patients, selected on the basis of providing data on "clinically relevant patient outcomes," Ballantyne et al. (152) found that PCA patients reported greater satisfaction and pain relief than those administered anesthesia in the conventional fashion. Christensen and colleagues conducted two studies (153,154) in which patients with end-stage renal disease being treated via staff-controlled, in-center hemodialysis (in which the patient is a passive recipient of treatment) were compared with patients being treated by home hemodialysis (CAPD), which requires the patient to take active responsibility for his or her own care. The only outcome difference between groups was poorer dietary adherence by the CAPD patients in the Christensen et al. study (153).

The studies in Group 4 address the question of whether patients should be given decisional control over treatment, especially in a situation where there is no strong medical rationale for favoring a particular treatment. The two major alternative treatments for early stage breast cancer (modified radical mastectomy and lumpectomy, usually followed by radiation therapy) yield similar survival rates (164). Lumpectomy is less disfiguring but some patients feel that mastectomy gives greater protection against recurrence and others are concerned about adverse effects of radiation (see 158); only "modest" psychosocial adjustment advantages have been found for breast conserving surgery (165). Of the Group 4 studies, only the results reported by Morris and colleagues (158) appear to clearly favor patients who were given a choice of treatment.

Conclusions: The studies in Group 1, along with others which did not collect patient outcome data (e.g. 166–168), demonstrate that patients may be readily influenced, via prior training, informa-

TABLE 2
Studies Evaluating the Effects of Conditions Designed to Give Patients Control

Study	Subjects	Experimental Design	Independent Measure of Control?	Outcomes
Group 1: Patients Exposed to Conditions Designed to Encourage Control Behavior with Their Physician				
Greenfield et al. (12)	45 peptic ulcer disease outpatients	Experimental patients: Encouraged to ask questions, negotiate decisions; Control patients: Standardized information	Yes; Experimental patients emitted more "controlling utterances" with physician	Experimental patients: fewer physical and role limitations; No group difference in satisfaction
Greenfield et al. (147)	59 diabetes outpatients	Same as above	Yes; Experimental patients more able to elicit responses from physician via their "controlling" verbal behaviors	Experimental patients: Lower HbA, fewer functional limitations and days lost from work, better overall health
Rost et al. (148)	61 hospitalized diabetes patients	Experimental patients: Showed how to take active role with physician and influence course of care; Control patients: Evaluation and educational program	Yes; Experimental patients asked more questions and exhibited more decision-making behaviors	No differences in recall of discharge recommendations, satisfaction, or HbA
Group 2: Patients Exposed to Conditions Designed to Influence Their Perception of Control Over the Treatment Environment				
Cromwell et al. (149)	183 hospitalized cardiac patients	Patients given high or low information, opportunity or no opportunity to engage in behavioral control activities, or high or low "diversion"; Factorial design, no control group	No	Patients given high information and either participation in behavioral control or high diversion spent less time in coronary care unit and were discharged from hospital earlier
Lazure and Baun (150)	60 hospitalized cardiac patients	Experimental patients: Given device to control timing of visits to room; Control patients: Not provided device	Yes; Experimental patients reported greater perceived control over visits than control patients	Experimental patients had lower mean heart rate and diastolic blood pressure; no group differences in perceived stress or on other physiological measures
Ziemann and Dracup (151)	41 hospitalized cardiac patients	Experimental patients: Nurse negotiated contracts with patients (re: visitation, time of hygiene care, room arrangement, etc.) designed to increase sense of control; Control patients: No contracts	No	Experimental patients reported lower anxiety, depression, and hostility at 24- and 48-hr follow-ups
Group 3: Patients Given Treatments Thought to Differ in Degree of Behavioral Control Afforded Patients				
Ballantyne et al. (152)	15 studies of postoperative patients (total $N = 787$)	Meta-analysis; Experimental patients: Used patient-controlled anesthesia (PCA) for pain control; Control patients: Used conventional anesthesia	No; Assumption that PCA involves more self-direction by patient (and therefore patient perceives self to have more personal control)	Experimental patients reported greater satisfaction and greater pain relief; No group differences on length of hospital stay, analgesia use, or side effects
Christensen et al. (153)	53 end-stage renal disease patients	Comparison of patients using home dialysis (CAPD) and patients receiving in-center treatment; Patients were not randomly assigned	No; Assumption that CAPD involves more self-direction by patient (and therefore patient perceives self to have more personal control)	CAPD patients were poorer in dietary adherence as measured by serum K; No group differences in adherence as measured by interdialytic weight gain or in self-reported depression
Christensen et al. (154)	86 end-stage renal disease patients	Same as above	Same as above	No group differences on measures of dietary adherence or self-reported depression

TABLE 2
Continued

Study	Subjects	Experimental Design	Independent Measure of Control?	Outcomes
Group 4: Patients Given Treatment-Relevant Decisional Control: Breast Cancer Studies				
Fallowfield et al. (155); Fallowfield et al. (156, 157)	118 Stage I or Stage II breast cancer patients	Patients given choice of type of surgery compared to no-choice patients; Group membership based on whether patient was treated by surgeon who offered choice; assignment not random	No	Lower self-reported anxiety and depression in patients treated by surgeons who offered choice; No differences in patients who actually exercised choice vs. those who did not (findings stable across 3-yr follow-up)
Morris and Ingham (158); Morris and Royle (159, 160)	30 Stage I or Stage II breast cancer patients	Patients given choice of type of surgery compared to no-choice patients (all of whom had mastectomy); Group assignment not random; patients matched post hoc for stage and age	No	Choice patients (and their husbands): lower self-reported anxiety and depression; Choice patients: better work adjustment and feelings about future, better coping with cancer; Choice patients' husbands: less concern about disease recurrence
Levy et al. (161); Levy et al. (162)	191 Stage I and Stage II breast cancer patients	Patients given choice of type of surgery compared to no-choice patients; Group assignment not random	No	Only comparisons made at 5 days postsurgery; No group differences on six self-report measures of emotional distress; among patients who had lumpectomy, choice patients reported greater depression, anger, and total distress
Pozo et al. (163)	63 Stage I or Stage II breast cancer patients	Patients given choice of type of surgery compared to no-choice patients; Group assignment not random	No	No group differences on multiple self-reported measures of psychosocial adjustment at 3, 6, or 12 months follow-up except for higher life satisfaction for choice patients at 3 months

tion, and encouragement, to emit increased levels of control-related behaviors during their interactions with physicians. In both Group 1 and Group 2, the control behaviors engaged in by patients were explicitly sanctioned by the health care team. This communicated to patients that they were thought by the staff to have the ability to actively participate in their own care in meaningful ways, and likely contributed to the overall effectiveness of the interventions employed in these studies.

From a control standpoint, the studies in Group 3 are limited by the fact that no independent evidence was obtained that patients using home dialysis or PCA, in fact, perceived themselves to be in greater control than their counterparts, despite apparent differences in control-related activities inherent in the procedures. In treating end-stage renal disease, even home dialysis patients (who are presumed to have relatively high personal control) must deal with disease-related problems (pertaining to fluid intake, blood chemistry, diet management) that are likely perceived by them as relatively uncontrollable. Regarding PCA, Taylor, Hall, and Salmon (169) found, based on interview data from postoperative patients who had just discontinued use of PCA, that it was rarely described

as a way of gaining control over pain and was valued primarily as a way of not having to disclose the fact that they were experiencing pain to the nursing staff.

The findings of some or all of the Group 4 studies have been interpreted by many (e.g. 114,168,170) as indicating that patient choice results in diminished psychological and/or physical problems after surgery. Aside from the fact that the findings are far from uniformly positive in favor of choice, because of design confounds, no conclusions about the impact of decisional control can be drawn based on this research. In no study were patients randomly assigned to treatment groups that differed only in whether patients were offered choice of treatment, and thus any differences obtained could have been a function of other variables that covaried with whether patients exercised choice (e.g. positioning of tumor, whether the surgeon offered a choice).

SUMMARY AND RESEARCH ISSUES

Available data indicate that the modal patient is capable of assimilating information and making reliable decisions in his/her self-interest. This statement needs to be qualified because the data

are often based on patient (or in some cases nonpatient) responses to hypothetical scenarios that do not bear directly on their medical treatment, and (like the studies highlighting patient limitations in cognitive ability) do not use standardized measures and are almost always based on data obtained from "convenience" samples—leaving open the question of representativeness and generalizability to normative patient populations. Overall, however, these data along with findings that physician decisions often do not reflect patient preferences or values and may be influenced by factors not relevant to treatment effectiveness, reinforce arguments for giving patients a more active role in their own health care. They do not, however, bear on the questions of how to increase patient involvement or whether doing so will necessarily produce beneficial outcomes.

Available data indicate that patients generally respond positively to enhanced information provision. But very few information studies are conducted in stress-laden contexts where patients must use information to participate in decision-making or self-care activities. Promising findings have been obtained with some behavioral control interventions. However, definitive general conclusions about the effects of increasing patient decisional and behavioral control cannot be made because of the small number of heterogeneous studies in which control has been manipulated or investigated as an independent variable and because of experimental design deficiencies in some studies. The following are viewed as areas in greatest need of further exploration with sound research designs:

Patient Control Opportunities Available in Different Settings

Different health care situations are amenable to different types of control opportunities for patients. The Group 1 intervention studies show that chronic disease patients can be readily stimulated to emit increased control-related behaviors when interacting with their physician in outpatient-type settings. The interventions used with recovering hospitalized cardiac patients (Group 2), in contrast, were at best marginally related to their medical treatment and show that effective behavioral control procedures can be instituted without necessarily infusing patients with technical information or encouraging involvement by them in treatment-related decisions. These findings suggest that patients' sense of control may be augmented productively using other low-cost, noninvasive procedures such as giving them a choice of walking or being carried to the operating room via stretcher (171) or giving them access to their medical records if they so desire (172). Also meriting further exploration are procedures designed to enhance sense of control in terminal cancer and other chronic disease patients by teaching them how to manage areas of their life where they still can exert effective control (e.g. interpersonal, financial problems) but which they may have erroneously come to view as intractable because of their illness (173,174).

Measurement of Perception of Control

Research that has linked positive outcomes to exercise of control has found that the critical control variable is one's belief that he or she can influence the aversiveness of an event rather than some objective determination of whether control opportunities were available (7,8). As noted above, most patients do not view PCA in terms of it enhancing their control, even though it provides them complete behavioral and decisional control over medication administration. Other unexpected findings along these lines have been obtained. For example, Wallston et al. (117) found that seemingly objective control manipulations, such as giving chemo-

therapy patients a choice of three different antiemetic conditions versus assigning them to a particular treatment, produced no differences in self-report of perceived control, and Street and Voight (142) found that diabetic patients' coded control behaviors bore no relationship to their appraisal of their personal control over decision-making during their encounter with their physician. Thus, patients often are not impacted by treatment environments or interventions in accord with researchers' presumptions, and it is important to obtain independent data on their control appraisals.

Individual Differences

Patients differ in the degree to which they want to be actively involved in their own health care and measures have been developed to assess patient differences in desire for informational, decisional, and behavioral control as separate dimensions (18). In the informational control area, patients identified as information-seekers adjust better to stressful surgical and diagnostic procedures and are more satisfied when given detailed information, whereas their counterparts do better in low-information conditions (126). However, except for the studies by Christensen et al. (153,154) (which did not involve random assignment) and one inconclusive study with PCA patients (175), few attempts have been made to investigate the utility of matching patients differing in desire for behavioral or decisional control to conditions offering different levels of control (see 143,144). Furthermore, just as patients differ in desire for control, physicians differ in their receptiveness to patients taking an active role (14,89,100). Particularly in the decisional control area, where patient-physician control-related interactional dynamics are a central variable (176), research is needed to assess the role of patient-physician matches as determinants of the effectiveness of control-enhancing interventions.

Decisional Control

Controversy in the patient control arena continues to center on the question of giving patients decisional control over high-cost decisions in life-threatening situations where there is no clear best treatment and value judgments play a strong role (e.g. late stage non-small cell lung cancer [76]). As indicated by O'Connor et al.'s (177) finding that oncologists strongly support decision aids for information provision but the majority reject their use as an outcome measure, many physicians continue to be reluctant to delegate control in these situations. As a result, there are no published studies either evaluating the impact of decisional control using decision aids on perception of control or health outcomes for patients facing actual high stakes decisions (178) or studying the effects of shared decision-making in conventional physician-patient consultations in such contexts.

CONCLUSIONS

The traditional "paternalistic" model of patient care has been increasingly challenged in recent years. In its stead, a shared decision-making model in which patients are maximally informed and collaborate with their physician in arriving at treatment decisions is being strongly advocated in medicine. Recent development of decision aids that enhance patients' retention and knowledge of expected outcomes and that reduce their decisional conflict has done much to allay apprehension about patients' ability to meaningfully participate with physicians in the decision-making process. Actual level of patient participation in the typical practice setting, however, continues to be "out of step with ethical ideals" (17). But, although enhanced patient involvement is desirable from an ethical standpoint, patients do not always want control (18) and

may not respond well to it if they are not confident that they are capable of making a useful contribution (179,180; see 181). Overall, there is a paucity of research assessing the effects of increasing patient control on their response to treatment and quality of care. In particular, very few studies to date have been conducted in which patients facing critical decisions are informed of likely net health benefits associated with different treatments (via decision aids or other means) (see 182) and are then given different degrees of latitude in actually exercising choice. Such research, along with studies in which opportunities for behavioral control are systematically varied, are needed to determine the types of patients (as well as physicians) for whom and the clinical settings in which enhanced patient involvement will, in fact, produce improved patient outcomes.

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