



## Does Informing Patients of Options Support Patient Choice?

by Margaret Holmes-Rovner, Ph.D.

Patient choice is gaining popularity among policy makers as a tool of healthcare reform. Before embracing patient choice, however, we must critically analyze its effectiveness as a vehicle for such reform. Can increased patient choice succeed as a health care reform strategy? That is, what are the drivers of patient choice, and what are the likely outcomes in producing better health and expanding healthcare for more people? Further, does increased patient choice support patient autonomy? Based on recent research in the psychology of choice, I argue that, by itself, giving patients increased choice supports neither health policy reform nor patient autonomy. In fact, I claim that both rational reform and patient autonomy may instead be enhanced by less choice. The notion of “shared decision-making” affirms that healthcare professionals and patients will engage equally in the decision making process, though they may have different roles and perspectives. I posit that for true sharing to occur, choices presented to patients should include analyses that summarize the evidence for and against competing choices and should also identify the “best” choice from an individual utility maximizing standpoint.

I make this argument in the context of a concrete set of tools that are designed to support evidence-based patient choice. These tools are patient education materials frequently called “patient decision supports,” including booklets, internet sites, or videos designed to support individual patients making real-time decisions about their own health care. An example designed to help patients decide about treatment for early stage prostate cancer can be found at [www.prostatecancerdecision.org](http://www.prostatecancerdecision.org). Such “decision support tools” and “decision aids” are designed to summarize the evidence for and against each treatment option, including watchful waiting (no treatment), and to encourage patients to engage in the process of shared decision-making with their personal health care providers. Developers and users of these tools have recently established a set of standards designed to insure that the evidence presented gives a balanced view of each option--to inform patients rather than to persuade them to make a particular treatment choice. Using a Modified Delphi approach, a large group of international experts (IPDAS consensus group) recently formulated a set of standards for presentation of data about choices presented in a decision aid. The patient decision aid:

- Describes the health condition related to the decision.
- Lists the health care options.
- Provides the option of choosing none of the health care options (e.g. doing nothing).
- Describes what happens in the natural course of a health condition if none of the health care options are chosen.
- Has information about the procedures involved (e.g. what is done before, during, and after the health care option).
- Has information about the positive features of the options (e.g. benefits, advantages).

- Has information about the negative features of the options (e.g. harms, side effects, disadvantages).
- Has information about outcomes of options (positive and negative) and includes the chances they may happen.
- Has information about diagnostic tests and what the test is supposed to measure.
- Has information about the chances of receiving a true positive, true negative, false positive and false negative test result.
- Describes possible next steps based on the test results.
- Has information about the chances of disease being found with and without screening.
- Has information in screening about detection and treatment of disease that would never have caused problems if screening had not been done.

Conspicuously absent from this list is what the “best” answer is: what an individual utility maximizing model would suggest is the “best” answer for an individual with certain risks and what a population-relevant technology assessment would say the “best” answer is for a population offered the options being considered. In the shared decision-making and decision support movement, we have shied away from presenting a rational “best” choice. Population-relevant answers probably are not offered because decision supports are largely designed to help individuals. At the individual level, there are two reasons for not revealing a “best” answer. One is the belief that patients should always have the right to be “irrational” if they are fully informed. The other is that measurement error in model construction and in patient value elicitation is simply too large to support recommending specific choices as being the best for a particular patient. Health care professionals for well-intentioned reasons often do not present recommendations resulting from a technology assessment of information designed to directly aid patients in making decisions about their own health choices. However, I argue that in doing so they may ultimately defeat the very objectives they mean to endorse, both in terms of supporting healthcare reform and supporting shared decision-making and patient autonomy.

### **Does increased patient choice serve the interests of healthcare reform?**

A two-fold motivating factor for patient choice in healthcare reform is to decrease cost and utilization of health services while simultaneously pleasing the public by offering more control over health care. The assumption underlying this approach is what Wennberg has called the “rational agency” view of the patient role. Under this assumption, the fee-for-service system of paying providers for each service performed may perversely drive providers to act in their economic self-interest by performing interventions that are of marginal benefit to patients or even unnecessary. This theory suggests that patients’ self-interest is different from that of providers, and that deliberation will put the patient’s interest first. Undergoing medical tests and procedures is not always in the best interests of patients, so patients should accept only those that are necessary (or desirable) for their health. Tests and procedures have attendant discomfort, risk, and cost. The expected result under these assumptions is that demand for health services will decrease. Increased patient choice, therefore, will rationalize the system. Indeed, patient choice is driven by an emancipatory impulse that presumes that patients can be liberated from the old oppressive, paternalistic system by sharing in health care decision-making. Freire’s work in education and early bioethics scholarship (for example, see Katz), as well as other critical 20th century social theory, provide intellectual support for the notion of liberation through choice.

Let’s now turn to the results of shared decision-making interventions in the use of medical services. The evidence to date is that patient involvement in decision-making has decreased

demand in only a few clinical conditions, such as the use of hysterectomy, screening and treatment for prostate cancer, and the choice between mastectomy and breast conserving treatment (Whelan et al.). These are informative, if unusual, examples. Prostate cancer is a unique example where the perceived harms of treatment occur in the face of no improvement in survival. However, when provided with evidence-based information for many other clinical problems, patients often make the same decisions their doctors would make without patient involvement. Why is this so? Clearly one answer is that patients trust their doctors.

Additional social and commercial forces drive patient choice to increased health care utilization. As a culture, we appear to want “bigger, better, more,” and we want it faster and more efficiently. Contemporary patients are most likely to have higher demands for perceived quality and for new technology. An emerging issue for the new breed of “patients as consumers” is the increase in physicians feeling the need to persuade patients to discontinue care they judge to be futile. Since the 1950s, communication science has devoted itself to advertising that encourages us to buy more products. In health communication, the focus has been on effective health campaigns, meaning getting more people to attend health screenings and to support other public health campaigns. Responding to the twin imperatives of technology and screening campaigns, health media consistently tout “medical breakthroughs.” These forces to “do more” promise to counteract potential decreases in use of medical technologies produced by providing evidence-based decision tools to patients, especially if the choices are presented as a problem of shopping with all options paid for.

### **Does increased patient choice serve patient autonomy?**

I will leave aside questions of whether patients want to be independent in their decision-making, and roles of patients and providers in making health care choices. These questions have been well laid out by Quill and Brody, and by Schneider. When patients wish to share in decision-making with their providers through decision support tools, the question then becomes, “How much choice and what kinds of choices assist in supporting autonomy?” Quill and Brody argue that when physicians withhold their guidance they fail to use their attendant power appropriately. Equally, I believe the same argument holds when preparers of decision supports fail to display the best choices to reach particular goals. This reluctance to provide a weighted evaluation of options reflects a misunderstanding as to the moral requirements of respecting patient autonomy, and fails as well to take account of contemporary research on the psychology of choice.

A helpful approach to the autonomy problem is the “enhanced autonomy” model proposed by Quill and Brody. They reject the independent choice model because it reflects a limited conceptualization of autonomy. Instead, they propose a dialogue in which physician and patient aim to influence each other and which allows the patient to fully appreciate the medical possibilities. When the decision-maker (patient) has limited competence or information and the physician does not offer guidance, the patient cannot then benefit from the available expertise and support. Systematically laying out the pros and cons of each choice, as is done in good decision aids, is an important start. However, people have limited capacity to process information; recent research has amply demonstrated that the more choices we are asked to process, the less well we are able to do so. Furthermore, people become overwhelmed and are unable to choose at all when choices proliferate. Providing patients with the analytically “best” choice and the reasons for it makes the decision-making process simpler for patients while still allowing them to critically reflect on their values, goals, and preferences--that is, allowing them to make an autonomous decision. While it can be argued that this strategy simply substitutes the tyranny of expert science for the tyranny of expert physicians, I would point out that the flip side

of this argument is that either form of guidance can be used well. To withhold either advisory method on the assumption that it might be influential is the worst form of paternalism.

### **The Paradox of Choice and Why More is Less**

In his recent book *The Paradox of Choice*, Barry Schwartz summarizes the literature on the psychology of choice arguing that the “culture of abundance robs us of satisfaction.” While his main intent is to empirically show that increased money and consumer goods in past half century have not brought happiness in the United States, his logic applies also to healthcare decision-making. In presenting treatment or screening options, the present state-of-the-art decision supports only provide a list of pros and cons for each choice. This list is helpful only as long as patients can go on to the next step to see their own appropriate logical best choice. Unfortunately however, the psychological evidence suggests that as the number of choices increases, decision-making requires more effort, mistakes in inference are more likely, and the burden of information overload leaves people prime candidates for regret and low satisfaction with their decision. As Schwartz points out, as the number of types of jams and jellies available in stores, increases, the less likely a consumer is to be able to make a choice.

Decision supports/aids are balanced, careful presentations of each option. However, they may work well only for those whom Herbert Simon and others describe as “maximizers”--people who want to know every detail of every option to make sure they make the objective (read rational) best choice. Providing the best choice from rational decision-analytic, cost effectiveness, and other technology assessment perspectives is one way of grouping options to simplify the data to answer a question. For example, “Which treatment is likely to let you live longest? If all the treatments are the same, what then are the differential side effects of each?” Or if cure is the objective, the decision aid can answer the question, “Which treatment is most likely to result in a cure? How much more likely, and with what side effects?” Withholding these answers is likely to force a patient to put her energy into trying to figure them out independently, rather than into consulting both the physician and the science to make an autonomous choice.

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## A British Perspective on Patient Choice

by Leonard Fleck

Margaret Holmes-Rovner asks the question, “Does increased patient choice serve the interests of health care reform?” I want to address that question from the British perspective, specifically, the perspective of NICE (the National Institute for Clinical Excellence) and the NHS (National Health Service). Britain spends only half as much on health care (as a fraction of GDP) as we do in the US, roughly 8% vs. 16.5% (2006). But the British health care system is besieged with the same costly advances in medicine that we face in the United States. Given their other social priorities, they cannot afford to buy as much of this expensive care as we do.

The role of NICE (created in 1999) is to do very careful evidence-based cost-effectiveness studies of all these new medical interventions for purposes of determining what will or will not be covered by the NHS. NICE is comprised of experts from a range of medical and nonmedical disciplinary areas who are ultimately responsible for deciding what will or will not be included as part of NHS coverage. They are deliberately isolated from typical interest group pressures and political horse-trading, which could skew their judgment, but they have a sophisticated approach to eliciting representative public input, especially with regard to value trade-offs integral to these judgments.

To return to Holmes-Rovner’s question, one clear outcome of NICE is that it does restrict patient choice, but it is in the service of health care reform (making wiser, fairer, more cost-effective choices). One major reason why health reform efforts have consistently failed in the U.S. is that we have a highly fragmented system for financing health care, which means that we cannot have effective, wise, or fair mechanisms for controlling health costs or making difficult rationing decisions.

In theory managed care plans ought to have strong motivations to control costs. In practice (because of widely circulated medical horror stories in the 1990s) managed care has minimal capacity to make painful rationing decisions (for fear of losing “customers” to competitors who would be perceived as being more “patient-friendly”). Likewise, managed care plans cannot afford to alienate physicians by being miserly in reimbursements since that too could result in lower quality care and “customer dissatisfaction.”

Employers have at their disposal effective but unwise mechanisms for controlling health costs, such as high copayments or deductibles, as in Health Savings Accounts. What the RAND experiments showed, however, was that patients faced with such cost-control measures were just as likely to make wise choices as unwise choices so far as reasonable medical self-interest was concerned. Cost barriers are indifferent and uninformative with regard to the value of the health care behind those barriers.

One would expect government to have the capacity to put in place fair and effective cost controls, but the Medicare prescription drug benefit (Part D) is powerful evidence for the exact opposite of that expectation. The rhetoric of the Bush administration was that patients would be given the choice of several hundred prescription drug plans, and this was clearly preferable to a

single government-determined plan. But the reality was massive consumer confusion, escalating costs, and increased inequities in access to needed healthcare. This was primarily because Big Pharma built into the legislation authorizing Part D a prohibition against Medicare bargaining directly with the large pharmaceutical makers. The result has been drug discounts for consumers in the vicinity of 15% instead of 50%, and ten-year projected costs to Medicare for Part D of about \$800 billion instead of \$400 billion.

Finally, with a highly fragmented financing system each insured patient “stands alone.” Moral arguments aimed at persuading patients to give up what “society” or some set of “healthy experts” regard as marginally beneficial non-costworthy care will fall on deaf ears, especially if that service is a covered benefit for that patient. Why, such a patient will ask, should they give up a benefit (even a very marginal benefit) if they have already paid for it? A society-wide deliberative conversation could both educate and motivate better (fairer, more cost-effective) decisions in such circumstances, but the isolation of individuals in insurance plans practically prevents such conversations. Consequently, health costs within plans increase rapidly, thereby driving more individuals into the ranks of the uninsured where they have no choices, informed or uninformed, a very nasty outcome. Better to choose NICE.



## Choice: A Privilege for Those with Health Insurance

by Heidi Connealy

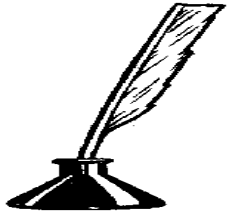
*Department of Anthropology, Ph.D. candidate*

For the past 14 months, I have conducted dissertation research in the form of participant observation and in-depth interviews at a Lansing nonprofit that provides a variety of “safety net” services to help low income individuals meet their health, food, and wellness needs. The primary focus of my research is to observe the role of the non-profit in public health promotion and wellness management in the wake of privatization and decreased funding of public social services. Many of the people who rely on this non-profit have difficulties getting everything they need to stay healthy. Most of these individuals are confident, savvy, and capable of making decisions about their health but lack the means with which to gain necessary health care, medicine, and food.

During my research, I have conducted health outreach, assisted with a number of health programs, acted as an advocate for people in need of public services like food stamps and Medicaid, and helped people enroll in the Ingham Health Plan (IHP). Managed by the Ingham County Health Department, IHP provides primary care and limited drug coverage to low income individuals without health insurance. The IHP is a laudable endeavor that has improved access to care for its participants. However, many individuals with serious acute and chronic conditions find the scope of IHP limited. Although a majority of the non-profit participants with serious health problems meet the financial requirements for Medicaid, very few are able to enroll; new enrollment in Medicaid is largely limited to pregnant women, disabled adults, children, and new refugees. Many people who would be eligible for Medicaid if they became officially disabled continue to work because they cannot afford to live on the amount of money allotted to them through Social Security.

The lived realities of the individuals served by this nonprofit suggest that patient choice and autonomy are luxuries reserved for Americans enrolled in private or public insurance plans. My observations lead me to conclude that patient choice and autonomy have little relevance for the 45 million Americans without both health insurance and regular access to care.





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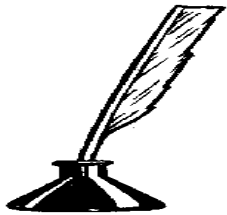
## The Need for Generosity and University Support

by Judy Andre, Ph.D.

I am teaching a new course this spring, “Ethical Issues in Global Public Health”(PHL 491). The issues raised by David Ubogy and Suzanne Schneider belong squarely within it--but in both cases are questions that could easily be overlooked.

A first, gut-level response to the overwhelming amount of disease and death in the world is simply, “We must give more.” Most of the diseases are preventable or at least curable: diarrhea, malaria, tuberculosis, and AIDS are major killers in poorer countries. Yet the Bill and Melinda Gates Foundation, by far the largest philanthropic organization in the world, does not just “give.” It invests in research, it builds infrastructure, it chooses among projects. Lessening the suffering in the world requires generosity--far greater than most people and countries now show--but it also requires an intelligent understanding of how the world works. Make that “worlds.” Haitian physicians threatened by violence live in a different world than Mexican community groups threatened with invisibility. Ubogy can tell us about Haiti because of his own generosity--he practices medicine there--but also because of his ethnographic research. The same kind of work underlies Schneider’s findings. To make a real difference in the world, all kinds of research are needed: bench research, for instance, because having the genome of, say, avian flu is crucial to tracking its spread; economic analysis that asks what the connection is between money and health (the answer is not simple); and engineering at its most creative is also needed so we can think about how, for instance, can vaccines be kept cold across long tropical distances.

The work of a university supports all these sorts of intellectual, creative, and practical endeavors. Ubogy and Schneider provide important examples of the way the life of the mind underlies the openness of our hearts.



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## (Re)Examining Medicine, the State, and the Market in Morelos, Mexico

by P. Sean Brotherton, Ph.D.

Modernization campaigns throughout the world, including in Mexico, have resulted in the pre-eminence of scientific medicine, especially biomedicine. Yet eradicating natural and traditional approaches to medicine has proven difficult in many parts of the world. As anthropologists have long argued, economic necessity, among other social-political factors, is key in sustaining this situation. Suzanne D. Schneider's essay, "Community Health Groups and the Changing Terms of Health Care in Mexico," provides an ethnographic case study of the increasingly politicized terrain in which struggles over access to health services, both biomedical and alternative medicine, take place. One significant factor in this situation is the slow withdrawal of the state in the political economy of health care.

Following anthropology's hallmark of *micro*-studies, which analyze circumscribed social groups, Schneider's essay provides a compelling examination of the deleterious effects of far-reaching neoliberal economic reforms on local communities. She focuses on the tenuous state-society dyad to chronicle the battle among various interests groups and, ultimately, the state. The increasing commodification of health care in Mexico's crippled economy has resulted in socio-economic class determining differential access to health care. This unequal access has produced vociferous responses among grassroots social movements. By drawing on a case study of community groups in Morelos, Mexico, Schneider documents how such grassroots social movements--those that organize around alternative medicine and are critical of the putative dominance of biomedicine--attempt to address the need for affordable health care among certain sectors of the population.

Schneider's argument is persuasive. I believe her argument would have been further strengthened by a brief examination of the equally detrimental *macro*-economic practices that shape and influence the political economy of health care in Mexico. The latter would entail a more explicit detailing of Mexico's role in the global economy. Mexico's health care sector is a microcosm for the broader social-political changes that Mexican citizens are currently experiencing due to a ubiquitous free market and foreign investment capital, as well as neoliberal economic reforms being imposed by international governing bodies (e.g., IMF, World Bank). For example, economic reforms in the 1980s and 1990s, enacted under the auspices of the nation-state and mandated by the IMF and World Bank, have led to the devaluation of the Mexican peso and to Mexico joining the U.S. and Canada to form the North American Free

Trade Agreement in 1994. These are all key factors in any discussion of the massive restructuring of health care delivery in 21<sup>st</sup> century Mexico. Transnational networks of governance in Mexico, as elsewhere, are complicit in the intermittent flow of capital, human labor, and, importantly for Schneider's case study, the circulation of medical knowledge and expertise (biomedical and alternative).



## News & Announcements

### Judith Andre

- Serves as a consultant for the Ethics Committee of the Rehabilitation Institute of Michigan.
- Participated in an Ethics Grand Rounds on the subject of atypical treatments for vulnerable patients. Lansing, MI (Feb).

### Len Fleck

- Gave lecture “Health Care Reform: Opposition, Obstacles, Opportunists” for MSU Undergraduate Bioethics Society (Jan).
- Participated in the “Disability and Bioethics Working Group” at the Cardozo School of Law. This research project is sponsored by Montefiore Medical Center and the Center for Ethics at Yeshiva University. New York City (Jan).
- Published “Just Caring: The Challenges to Priority-Setting in Public Health” in *The Blackwell Guide to Medical Ethics* (2007), edited by Rosamond Rhodes, Leslie Francis, and Anita Silvers.

### Linda Hunt

- Published (with co-authors H. Castaneda and K.B. de Voogd) “Do Notions of Risk Inform Patient Choice? Lessons from a Study of Prenatal Genetic Counseling.” *Medical Anthropology* 25(3): 193-219 (2006).
- Published (with co-author H. Brody) “BiDil: Assessing a Race-Based Pharmaceutical.” *Ann Fam Med* 2006 4: 556-560.

### Ann Mongoven

- Published “The War on Disease and the War on Terror.” *Cambridge Quarterly of Healthcare Ethics* 15(4) 403-17, Fall 2006.
- Gave lecture on “Religious (?) Refusals (?) of Treatment (?)” for MSU College of Osteopathic Medicine diversity workshops series (Sept).
- Presented “Gift of Life or Relay of Life? Organ Donation in Comparative Perspective, U.S.-Japan” for MSU Asian Studies 2006-07 Colloquium Series on Biotechnology and Society in Asia (Oct).
- Gave talk “All is Fair in Love and War? Tendencies in American Organ Donation and Transplantation Policy” for the MSU premed society (Oct).

### Harry Perlstadt

- Published “Ethical Dilemmas in Publishing a Journal of Public Health Practice.” *The Michigan Journal of Public Health* Vol. 1, no. 1 (2006).