From the Director

Anyone who had to decide recently among the new Medicare drug plans - or help an older relative do so - knows some of the challenges involved in making the best decisions about our health care. This timely lesson in how more choice can be problematic is a modern challenge that vexes doctors and patients alike.

Increasingly, doctors are working to make the best treatment choices under conditions of uncertainty, as well as pressure to reconcile their decisions with patients' desires. This is a far cry from the days of Marcus Welby, MD, a benign, paternalistic television doctor who made all the decisions about his patients' care and was always right. The shift has affected patients as well, who are suddenly involved in decisions about their care in ways they have never been before.

But what, exactly, has changed? Why all the uncertainty?

- The complexity created by burgeoning knowledge, technology and treatment options has swamped doctors' abilities to always know the best choices for their patients.
- Norms of practice are shifting from doctor dominance to "shared decision-making" that require physicians to take into account patient preferences and expectations as well as their own evaluation of the validity of scientific evidence.
- Decisions about care are increasingly entwined with concerns about its affordability.
- Information about genetics and from other screening options can alert people that they are at risk for disease, but often the degree of risk is uncertain and the effectiveness of preventive treatments isn't always clearly established.
- The Internet provides readily accessible health information to patients as well as to doctors, some of which is accurate and some of which is not.

In this turbulent environment, CHC researchers are working to improve the decision-making of both providers and patients. They draw on the predominant theories of decision-making - based largely on back page
In a modern, urban hospital, a woman gives birth to a 23-week-old baby girl, weighing just over a pound. As the child’s vital functions decline precipitously, doctors sadly conclude that resuscitation would be “medically futile” care. It’s a conclusion backed by research-based guidelines; even if the child survives, her life will be short and painful.

But the distraught parents refuse to accept that conclusion. Surrounded by miraculous technology and the tangled emotions of giving birth—and suspicious of a medical staff they believe has different cultural values than their own—the parents cling to hope. They demand their baby be put on life support. (On another day, with the circumstances slightly changed, the roles could easily be reversed, with the parents the ones who don’t want heroics.)

“Conversations like this are enormously difficult,” says Colin Partridge, MD, a UCSF neonatologist and researcher. “They can go awry for any number of reasons.”

They also illustrate the complex and high-stakes human calculus that characterizes so many medical treatment decisions. How do providers create humane, medically sound guidelines about treatment options? How do they collaborate effectively with patients and families in the midst of wrenching, life-altering decisions? What can and do patients and providers use to help them make these decisions? How do cultural gaps, ethical concerns, and legal and financial issues figure into the process?

Researchers at the Center for Health and Community are racing to find answers.

Life and Death in the NICU

“The idea (in making treatment decisions about very low birth weight infants) is for physicians and parents to work as much as they can towards consensus in the best interests of the baby, but who ultimately makes the decision can be a very gray area,” says Partridge. “It’s a delicate dance, with one partner (the physician) often offering a bit of a lead in exploring what the parents think is best. You need to be an effective communicator.”

Partridge is currently studying the impact of the 2002 federal Born-Alive Infant Protection Act on decisions in the NICU. “If enforced, the act could mandate resuscitation of infants not expected to live, because it insists there be no gestational age limit for providing appropriate medical care to ‘born-alive’ infants,” he says.

Understanding Hysterectomies

Miriam Kuppermann, a researcher in the Medical Effectiveness Research Center (MERC), is a past Trustee for the Society for Medical Decision Making. She is determined to help women with non-cancerous uterine conditions better understand their treatment options, which
usually include hysterectomy, a procedure that can have a profound emotional impact and about which there is considerable debate. In one randomized trial, Kuppermann and colleagues found that among women with prolonged, abnormal uterine bleeding, hysterectomy showed relatively favorable outcomes. "Six months out, women who were randomized to hysterectomy showed more improvement in terms of health-related quality of life and sexual functioning than those who were randomized to an enhanced medication regimen," says Kuppermann. Within two years, half of the women randomized to medicine had elected to undergo a hysterectomy, and both groups demonstrated substantial improvement.

In a second randomized study, Kuppermann and her collaborators found that the evidence didn’t support previous suggestions that hysterectomies which leave in part of the cervix allow for better sexual function than those that remove the entire cervix. The widely publicized results of both her studies have become important sources of information for patients and providers alike.

Kuppermann is now in the midst of a study of 1500 women from diverse racial, ethnic and socioeconomic backgrounds. The researchers will follow these women for eight years to determine what factors predict the use of hysterectomy and its alternatives, as well as the factors that predict satisfaction with these treatments.

**A Model System for Deciding on Breast Cancer Treatment**

The UCSF Carol Franc Buck Breast Care Center is one model of how informed decision-making can help patients.

“A decision is a conversation, a critical reflection that goes on until the point when resources are allocated irreversibly,” says Jeffrey Belkora, director of Decision Services at UCSF. In some medical situations (like an emergency room) that process can occur in just a few seconds; in others, such as those at the Breast Care Center, patients and providers might have weeks to ponder their decision.

Belkora and surgeon Laura Esserman, director of the Breast Care Center, wanted to implement a process that helps patients participate in their medical consultations, assures they understand their options, and helps them make trade-offs and settle on a decision that’s tailored to their goals. Belkora has developed “a practical framework for facilitating problem solving in high-stakes situations... The central principle is to divide the decision into separate categories and analyze them one at a time.”

At the Breast Care Center, once patients are diagnosed, they receive videos (created by the Foundation for Informed Medical Decision Making) and other information about their disease and treatment options. Then, they work with Decision Services staff to develop a Consultation Plan – a list of questions and concerns – for an appointment with their surgeon and/or oncologist. The Decision Services staff member accompanies the patient to the appointment, audio-records it, and takes notes. The patient leaves the meeting with a “Consultation Plan and Record,” which documents the questions they asked and the answers they received.

In studies done over the last decade, Belkora and colleagues have found, “Consultation Planning contributes to improved patient and physician satisfaction while improving communication. And in a post-decision survey, patients reported that Consultation Recording contributed to improved decision quality.”

**Decision-Making Disparities**

Unfortunately, most patients don’t have the benefit of this informed decision-making process.
Researcher Celia Kaplan is looking at some of the factors that limit the available choices. Kaplan is analyzing the results of a study of women throughout California who had ductal carcinoma in-situ (DCIS), a noninvasive, precancerous condition that some groups include in breast cancer statistics. Despite reports of Latinas receiving mastectomies for this condition more frequently than their non-Hispanic counterparts, very preliminary results found no significant difference in the mastectomy rate among white non-Hispanics, English-speaking Latinas (ESLs), and Spanish-speaking Latinas (SSLs). At the same time, there are indications that other treatment choices – radiation and reconstructive surgery – may have been limited by socioeconomic status (SES), geography, language, and culture.

For example, white non-Hispanics and SSLs who had a lumpectomy chose radiation less frequently than ESLs – but for different reasons. The former tended to make an informed and calculated risk judgment, based on knowledge that you can't have radiation for breast cancer more than once. If they have a recurrence, they want to have a choice to avoid the mastectomy. In contrast, SSLs indicated that nobody offered them radiation. Another preliminary finding is that after a mastectomy, SSLs were less likely to choose reconstructive surgery than white non-Hispanics, though the reasons are not yet clear.

“Were their language and education barriers that prevented providers from clearly offering the entire range of options?” Kaplan asks. “Were less educated, lower SES women less likely to choose reconstructive surgery because of the cost, lack of insurance coverage, or an unwillingness or inability to be away from work for the additional recovery time? We need to do more qualitative work to probe beneath these initial findings.”

### Creating Culturally Sensitive Decision-Aids for Prostate Cancer Treatment

Like breast cancer patients, prostate cancer patients face an array of treatment options, all of which provide a reasonable chance of survival, but have quality of life tradeoffs. Driven by indications that one in every four prostate cancer patients has regrets about their treatment choice, psychologist Sara Knight is trying to better understand patient preferences and creating tools to facilitate more informed choices.

“When people make decisions, they may not weigh things optimally and so end up making a decision that is not best for them and that they may regret,” says Knight. Her work at the San Francisco VA Hospital has led her to believe that some of those regrets may be connected to socioeconomic status and health literacy. She has zeroed in on the use of decision aids, many of which are less effective for low-income or low literacy patients.

“Creating decision aids that are appropriate for the population we are trying to serve is important. It's not just about getting them to choose the right treatment option, but also ensuring they understand the consequences of their choices.”

Knight and her colleagues are now designing, testing, and refining a new decision-aid tool.

### Of Chest Pain and Heart Disease

Of course, decision aids are not only for patients; providers need them as well. For example, despite having a battery of sophisticated diagnostic tools, determining if chest pain is actually a heart attack is often quite difficult, even for the most skilled diagnostician. Moreover, until cardiologist Lee Goldman's seminal work in the 1980s and 1990s, emergency room physicians only had...
two options for patients presenting with chest pain: admit them or send them home.

Goldman, now Chairman of the UCSF Department of Medicine, analyzed volumes of research to create a decision-making algorithm that essentially narrows the process of deciding how to handle potential heart attacks to ECG results and three easily answered questions: Is the pain unstable? Is there fluid in the lungs? Is the blood pressure below 100?

Goldman’s work also revealed that physicians needed an intermediate option, between admit and release. This led to the creation in hospitals across the country of chest pain evaluation units where physicians can monitor patients for an additional six to 12 hours. The combination of these units and the algorithm has proved to be extremely effective.

When Cook County Hospital in Chicago adopted Goldman’s methods, they made the correct call on the most serious patients 95 percent of the time. Without the algorithm, they were right between 75 and 89 percent of the time.

More recently, Goldman’s focus has shifted to the Coronary Heart Disease Policy Model, a comprehensive computer-simulation of the cardiovascular risk factors and events of the U.S. population.

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**Services**

Health care includes services such as screening, vaccinations, and reproductive technologies that involve more long-term thinking than the immediate demands of treating an illness. These add another dimension to how patients think about risk versus reward regarding their health.

**Colorectal Cancer Screening**

Colorectal cancer screening has proven to be effective in diagnosing a disease that if caught early is often curable; in fact, finding and removing precancerous polyps can actually prevent development of the disease. Nevertheless, fewer than half of Americans over the age of 50 have had colorectal cancer screening within the time intervals that national guidelines recommend. Health economist Kathryn Phillips heads a large, multi-site study trying to understand why despite the proven value and numerous efforts to encourage it, Americans continue to under-use this screening.

It appears that the problem is not just with patients, but also with their doctors, as Phillips has found that patients are more receptive to screening than their doctors think. “Part of the reason for the communication gap is that primary care physicians often have just one or two minutes with their patients to make relatively complex decisions around colorectal cancer screening,” says Phillips.

“As a result, many doctors pass up opportunities to offer screening – or poorly informed patients fail to follow through on what their doctor recommends,” says Michael Potter, MD, a UCSF researcher who is a co-investigator on the project.

To translate her findings into better clinical practice, Phillips is working with the UCSF Collaborative Research Network, a network of UCSF-affiliated community physicians practicing across the Bay Area and northern California. They are developing a decision tool that will take only 1-2 minutes for primary care physicians to use with their patients. “We hope that by making it easier for doctors and patients to talk effectively about testing options, we will make it easier for more patients to get the testing they need,” says Phillips.

**Genetic Fetal Testing**

For some time pregnant women, 35 and older, have been offered testing to see if their child has genetic defects that could lead to, among other things, Downs Syndrome. The age break is based on research that 35 is the age where the risk of...
miscarriage from amniocentesis equals the risk of having an affected fetus. “But those guidelines aren’t based on individual values and preferences,” says Miriam Kuppermann. She has found substantial variation in how women feel about miscarriage versus having an affected fetus – and that offering diagnostic testing to pregnant women of all ages can be cost-effective, depending on their values and preferences.

Kuppermann and her colleagues concluded that they needed a tool to help women understand what the tests entail and the risks involved, and to help them clarify their values regarding this choice. The researchers created and tested an interactive, computerized, decision-making tool and in a randomized trial found that it increased women’s understanding of the risks they faced, diminished their decisional conflict, and changed the choices they made.

The work garnered Kuppermann an award from Tmbioscience and the American College of Medical Genetics Foundation. She is using that award to create a “more clinically useful tool,” one that distills the tool to its essence, accounts for women’s literacy levels, and incorporates new genetic discoveries.

**Assisted Reproductive Technologies**

CHC researchers are also studying another critical choice some women have to make regarding pregnancy: use of assisted reproductive technologies, such as in-vitro fertilization. A multidisciplinary team is conducting a longitudinal study of patients seeking infertility treatment to provide better information to those facing the decision of whether to undergo treatment.

Despite uncertainty about the success of these technologies, when women come to fertility clinics, many want to hear hopeful messages and their physicians often feel pressure to instill that hope. “Consequently, women often underestimate the risks and fail to consider important, longer-term issues,” says psychologist Shana Millstein who is directing one component of this project. Her research has shown, for example, that women considering using a donor egg often fail to consider questions such as: Will they tell the child about their biological origins? Will the child have a relationship with the donor? What impact will that have on the child – and the parent-child relationship?

Millstein hopes her work will help those working in fertility clinics put greater emphasis on clarifying all of the risks and benefits of these technologies: the practical, the rational, and the emotional. Other team members will provide data on the emotional as well as the social and economic costs and medical outcomes of treatment, all of which can help patients make more informed decisions.

**Health Behaviors**

HC researchers have long made health behaviors a significant focus for their work. By understanding how people make decisions about health behaviors, researchers can help improve and inform public health initiatives that might, ultimately, help people avert some of the wrenching treatment decisions described above.

**Sex and Cigarettes**

Bonnie Halpern-Felsher’s research informs and improves programs to reduce or prevent behaviors such as unprotected sex, risky driving, smoking, drinking, and drug use among teens. Presently, she is tracking the sexual and smoking choices of 1000 teens from ninth grade into young adulthood and has found that teens understand some, though not all risks quite well. This raises questions about widely held assumptions regarding teens’ sense of invulnerability.

“We may not agree with their ultimate choices, but many teens in our sexuality study are clearly and rationally balancing risks and benefits,” says Halpern-Felsher. She notes that some chose oral over vaginal sex – a finding that garnered considerable press attention – precisely because they didn’t want to risk pregnancy and also believed (somewhat falsely due to lack
of education) that their choice eliminated the chance of sexually transmitted diseases.

"They wanted the benefits of sex – the social status, the pleasures – without the risks," says Halpern-Felsher. In fact, in a teenagers' world, *not* having sex can feel like more of a risk than having sex.

With smoking, teens seem to have a more limited understanding of the risks involved; in particular, many fail to understand how quickly an addiction can take hold. Even a bad first experience often didn’t rule out continued experimentation, because of the appeal some saw in tobacco – from the satisfying sense of rebellion to the way smoking can help people calm down.

Even when teens fully understand risks, says Halpern-Felsher, social pressures in the heat of the moment can negate their rational judgment. Moreover, recent brain research indicates the executive functioning (or decision-making) part of our brain is not fully developed until the early twenties. "To be more effective in helping teens through these decisions, we need intervention tools that account better for how teens think about their risk-taking behaviors," says Halpern-Felsher.

**Bringing Together Biology, Psychology, and Environment**

Shana Millstein agrees. Millstein is on the Institute of Medicine Board for Children, Youth, and Families, which has conducted a workshop on Adolescent Decision Making Competence.

Millstein herself is studying adolescents age 16-20 to determine how stress, often generated by social pressures, affects cognitive function and, in turn, decision-making. In a laboratory environment, young people are asked to perform stressful tasks, such as public speaking and solving math problems. After measuring stress levels using biological indicators (e.g. cortisol levels, heart rate, and blood pressure), researchers then test such things as memory, concept formation, and executive function.

"This work should help us better understand how biology, psychology, and environment interact," says Millstein. "That integrative paradigm is sorely needed if we're to have a real impact on how young people make decisions about their health behaviors."

**The Need for Collaboration**

In fact, nearly everyone doing research in this area stressed the critical need for collaboration across disciplines.

For example, epidemiologist Sara Johnson and economist Julian Jamison, two current Robert Wood Johnson fellows at the CHC, are working collaboratively on research that should amplify and expand the work of researchers like Millstein and Halpern-Felsher. Jamison's earlier work revealed that people prefer more options, but that having more choice leads to poorer outcomes. Johnson is building on earlier studies showing that high reactivity - a tendency to become stressed more quickly and more intensely - is associated with key cognitive functions. Combining Johnson's work with Jamison's experimental economic techniques to assess rational choice puts them in a better position to understand why teens and young adults make "bad" health decisions.

And psychologist Knight has worked collaboratively with health economist Phillips and decision-making expert Belkora to develop or refine their various decision-making aids. "Cooperation – collaboration – is so important," she says. "We need contributions from many disciplines to create a truly refined understanding of how medical decision-making works."

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on economic principles of rationality — but extend these principles to consider some of the factors that may derail the process of reaching an optimal decision. They address questions that include: What is the role of stress in medical decisions? How do social forces change health-related decisions? What information do people need to make fully informed decisions that are consistent with their values and preferences? How can we create and test decision aids to further the goal of fostering a healthier population?

The cross-disciplinary nature of this work is precisely why the Center for Health and Community (CHC) is an ideal place to conduct this research. As this issue of Exchange demonstrates, many of our members are among the field’s leaders, breaking important new ground that benefits patients and providers alike.

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Using the model, researchers run “what-if” scenarios of the clinical and cost-effectiveness of a wide range of preventive interventions for heart disease, such as lowering cholesterol or blood pressure. “Essentially, it looks at the bang for the buck of interventions in terms of what we call quality-adjusted life years,” says Goldman.

The project can have a powerful influence on policymakers and disease management programs. For example, in 2002 Goldman and others caused a stir when they published a study showing that the increased use of aspirin was more cost-effective in preventing heart disease than use of a “super” aspirin called Clopidogrel. Upcoming initiatives include detailed analyses of the impact of smoking and second-hand smoke.