

community partnerships prevention environmental hazards burden of illness managed care culture fertility beliefs and values barriers to access diversity innovative research women's health disability health policy homelessness communication quality improvement violence aging outcomes substance abuse ethics technology stress placebo youth gene testing information and decision making morbidity and mortality poverty patient satisfaction e-health work conditions e-registers risk factors population health

exchange

the Center for Health *and* Community

at The University of California, San Francisco

From the Director

In our first issue of this newsletter we discussed the growing disparities in health in the US and around the world. In this issue, we highlight research on the human impact of new biomedical and information technologies. In their own way, these technologies symbolize the harsh reality of social disparities. Advanced scientific procedures and vast amounts of digital information have the power to impact decisions, change behavior, and improve health for those who can afford, access, and understand them. The less privileged—whether by education, finances, or social status—are less likely to reap the benefit of these advances.

New technologies offer promise of longer and healthier lives; fulfilling this promise requires more than simply developing the technology. Too often, new technology creates excitement that rushes it to market without being informed by a genuine understanding of clinical practice or patient needs. As a society—and as a center of research—we have a responsibility to make sure our understanding of how these new technologies affect us keeps pace with their rapid development. This means perspective—the longer, broader, and deeper view.



Faculty at the Center for Health and Community offer that view. Working in the heart of research on new biomedical and information technologies places us in an ideal position to raise important questions about technology's role in health care. Our work is unique because it is a collaboration at the critical nexus of behavioral, social, biomedical, and now medical informatics research. Interdisciplinary work like ours can humanize medical science and bioengineering by revealing the concerns of the people and communities technology is supposed to help.

It is exactly this type of research that can help ensure that we not only avert the dire scenarios that science fiction and some social commentators have foreseen, but also realize the stunning potential of technology to improve health, reduce costs, and extend health services to all those who need them.

Nancy Adler



In This Issue

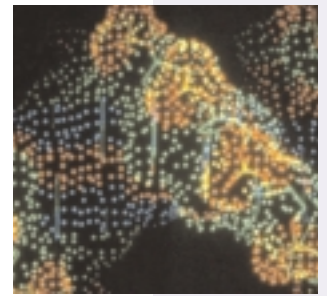
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The mission of the Center for Health and Community is to:

Facilitate multidisciplinary research that will provide more comprehensive understanding of problems of health, illness and health care

Develop and test new strategies for research and interventions to promote health, prevent disease and facilitate recovery

Provide more integrated teaching of basic and applied aspects of social and behavioral sciences, epidemiology and health policy to students in all four professional schools

Establish collaborative partnerships with community groups that enable the Center to fulfill its educational, research, and service priorities

There is probably no more ardent advocate of the long view than Adele Clarke. Clarke and her colleagues add historical, sociological, and anthropological perspectives to the CHC's interdisciplinary approach. "The advantage of our humanities-based work is that it allows scientists, policy makers, practitioners and engineers to stop and think about how we got to where we are," says Clarke.

Clarke's research focuses on how health-related technologies (contraception, RU-486, pap smears) have shaped our attitudes towards our bodies, our health, and our medical care—and how our attitudes and cultures have shaped the technology. A recent paper examines how contemporary biosciences and technologies drive health concerns deeper into all aspects of people's lives than they have ever been before. She argues that because biosciences and technologies allow us to do so much, and information technologies (IT) drive heightened awareness, people suddenly have much greater responsibility for their own health. We perceive ourselves and what is possible in entirely new ways. Much of the research described below seems to confirm that analysis.

Genomics

John Ziegler is using genetic testing to help patients avoid and survive cancer, both through direct care and cross-disciplinary research that helps refine and advance current treatments.

"About ten percent of many common cancers are familial," says Ziegler, a physician and epidemiologist. "In families with an excess of cancers, genetic counseling and testing for mutated genes can identify people at higher risk. These people can then take precautions to avert the disease or detect it at an early stage."

But Ziegler notes there is still considerable uncertainty about the best clinical options. He wants to understand how to use advances in genetics to discover optimal combinations of preventive surgery, hormones, chemoprevention, lifestyle changes, and screening procedures.

To do this, he and his colleagues in the UCSF Cancer Risk program are gathering a study group of families at high genetic risk of breast or colon cancer. These families will benefit through focused attention to preventive and treatment measures, while also providing fertile ground for observational studies and randomized clinical trials across various disciplines.

Behavioral scientists, epidemiologists, and clinicians will use the research from this cohort to improve care and services for cancer patients.

“In families with an excess of cancers, genetic counseling and testing for mutated genes can identify people at higher risk.”

CHC researchers:

- Use new technology to improve care
- Foster wiser user of advances in reproductive technology

Ziegler and the Cancer Risk Program are already putting advances in genetic testing to work, but Kathryn Phillips believes that in order to fully realize genomics' vast potential, we must get a better grasp on its economic and social implications. Phillips notes, “There have been few published analyses of the cost-effectiveness of genotyping—and few insurers cover any type of testing.” Consequently, she and a cross-disciplinary team are using genotyping to treat HIV as a way to begin measuring the costs and benefits of using genetic information in the development of new drugs, as well as the costs and benefits of individualizing drug therapies. Among the important questions the work will address: What conditions dictate the need for genotyping as standard practice? How can we ensure it is equitably delivered? What structures would better facilitate its use?

Infertility Treatment

Just as genomics is changing our perception about what is possible in the treatment of certain conditions, new technologies are changing our perceptions about the entire concept of reproduction. Ten percent or more of married couples struggle to get pregnant and these struggles can significantly disrupt people's lives. But while reproductive technologies offer new hope, they also create troubling dilemmas, which our faculty are addressing.

Gay Becker is an anthropologist whose work often focuses on people experiencing serious, health-related disruptions in their everyday lives. Through in-depth interviews, Becker recently completed a study that explores what she calls “the moral dilemmas created by the marketing of new reproductive technologies.” Many of the people revealed, for example, that in vitro fertilization (IVF)—which is only successful 20-25 percent of the time—exacted a real price on their finances and on their marriages. Moreover, IVF challenged some of these peoples' most closely held ideas about bearing children, including what it means for a birth and/or a child to be “natural” and how that meaning has changed.

The study also points the way to needed research. For example, what are the effects on individuals and society of insurance not covering these expensive treatments? What is truly driving the

use of in vitro fertilization (IVF)—profit or genuine health concerns?

For some of the questions Becker's study raises, CHC faculty Patricia Katz, Susan Millstein, Mary Croughan-Minihane, Lauri Pasch and Nancy Adler may soon have some answers. They have designed a unique program project called Individual, Family, and Societal Outcomes of Infertility. The project involves four separate but connected studies funded by the National Institute of Child Health and Human Development. Because of the size of the study population (500 couples in the three connected studies, 6000 women in the fourth) and the broad scope, the project will offer some definitive insights into the effects of infertility and infertility treatments. Katz notes the unique design stems from a fundamental idea: “People are complex beings in a complex world,” she says, “If we're trying to address these questions we have to look at them from many different perspectives.”

One component study will examine how couples make the many decisions associated with the use of assisted reproductive technologies. It will look closely at how much providers understand about their patients' psychological vulnerability when they discuss the chances of success and the potential risks for both mother and child.



The second study in the project examines psychological effects of using IVF, in particular the effects of repeated failure. The study will help identify women who are most at risk for psychological problems resulting from their use of IVF. This information should help those most vulnerable get the support they need to make decisions and to help navigate the consequences if they choose to move ahead.

The third study looks more broadly at the social and economic costs of IVF. These include direct costs, indirect costs of time and stress and social costs. Among the social costs is differential access; because insurance rarely covers it, this technology is only available to those with enough disposable income to afford it.

Finally, patients undergoing infertility treatment are not merely concerned with getting pregnant; they want to have a healthy baby. The final project is examining pregnancies in women with a history of infertility or who conceived using infertility treatments and comparing their outcomes with those of women in the general population. This research will identify complications during pregnancy, labor, and delivery, as well as pediatric outcome in the children up to age six that may be associated with infertility and/or infertility treatment.

“Assisted reproductive technologies are still relatively new. If we can better understand the impact on people’s lives, we can better ensure that people will benefit from the advances rather than suffer because of them,” says Katz.

Increased access to health information coincides with and is helping to drive an effort within the US health system to move decision making directly into the hands of those who consume the care. CHC researchers explore the implications of this movement and develop structures as well as the technology itself that turns theory into practice.

Fostering Improved Health Literacy

Functional health literacy (FHL) is the measure of how well people read and comprehend medical information, which is quite different from traditional reading or educational level.

Health literacy is an issue for patients who speak English as a second language and those with lower education levels, but primary care physician Dean Schillinger warns, “Most of the materials we hand out are way above the literacy level of the average patient and this issue should not be marginalized.”

Schillinger is conducting a study that measures the association between FHL and disease outcomes, and examines if

and how we can integrate an understanding of FHL into the way we communicate with patients. The study looks at patients on a blood thinner for atrial fibrillation. Such patients achieve success only half the time. Rather than give these patients their medication instructions in traditional ways, Schillinger will use a desktop software program to create a tailored pictograph (instructional picture) to help patients follow their regime. “If we can establish that this method leads to better care, maybe we can change the way we label and distribute drugs,” says Schillinger.

Physician Adams Dudley and economist Hal Luft are also concerned with labeling but of a very different sort. The two researchers are developing a way for purchasers of health insurance (employers and individuals alike) to compare plans based on genuine, in-depth quality measurements as opposed to simply price.

There have been efforts to create health plan “report cards,” but to date these have been inadequate because they offer so little information about clinical outcomes. Dudley and Luft believe that modern information systems may provide better ways to measure quality, so consumers could more easily gauge how effectively plans manage or treat specific conditions.

“Quality suffers because the incentives are out of alignment...

but if we have quality data and use it to reward physicians providing

quality care, the dynamic might change.”

CHC researchers:

- Address functional health literacy
- Create more useful measurements of health plan quality
- Reduce health-risk behaviors and provide support by reaching out to a broad range of people and communities
- Empower patients to take control over their health treatments

By working with clinicians, electronic data from four major health plans, and thousands of medical charts, Dudley and Luft's work will establish what combination of today's electronic and paper-based data will predict both quality outcomes and costs. The study will also attempt to bring that information together electronically, so it can be compiled quickly and displayed in a way that purchasers can make sense of its implications.

“All of people's anger about managed care is related to quality,” says Dudley. “Quality suffers because the incentives are out of alignment; people are paid more to provide less care. But if we have quality data and use it to reward physicians providing quality care, the dynamic might change.”

Supporting Choices about Health Behaviors and Treatments

CHC researchers are also developing ways to use IT as an intervention tool to encourage healthy behaviors as well as to help people make more informed decisions about their health-related behaviors and medical treatments.

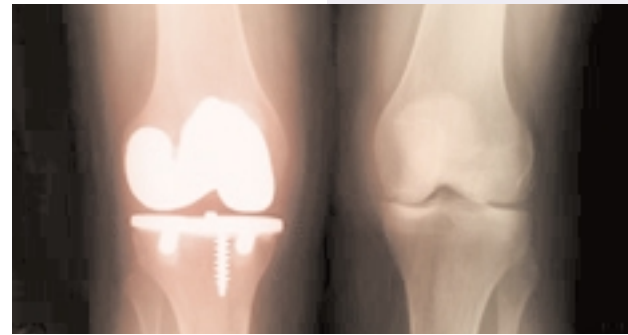
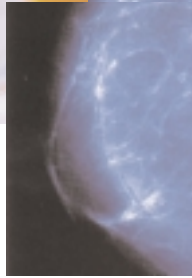
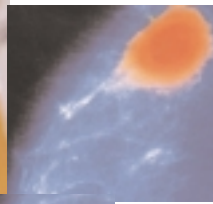
Psychologist Ricardo Muñoz believes that IT may be a tool that can help people stop smoking. “One-pack-a-day smokers spend about \$1000 a year for their habit and add enormous treatment costs to the system,” he says. Yet many smokers who want to quit are unable or unwilling to attend smoking-cessation clinics. Muñoz and colleagues, psychologist Barbara Van Oss Marin and physician Eliseo Pérez-Stable, have already shown that they could provide effective interventions through the mail to help Spanish-speaking smokers quit. In a randomized trial, the researchers compared the 3-month quit rate for people who received a smoking cessation guide with the 3-month quit rate for people who received the guide plus a mood management method. The addition of the mood management method doubled the 3-month quit rate to 23 percent. Now Muñoz and his colleagues are preparing to replicate this study on the Web.

Muñoz, who directs the Latino Mental Health Research Program, notes that the study is looking at new ways to reach out to communities and could

bridge the digital divide for Spanish speakers. “Perhaps we can eventually collaborate with health plans to offer the equipment for Web access to Spanish-speaking smokers with children. After a year, the person could either buy the equipment at a cost considerably less than their smoking habit or simply return it. In addition to quitting smoking and reducing exposure to second-hand smoke to their children, it would provide the entire family with access to the Internet as a non-trivial side benefit.”

Smoking, of course, is only one of a number of health-related behaviors that contribute prominently to premature death in the US. Barbara Gerbert's most recent research focuses on designing and testing innovative interventions that could help patients reduce their smoking, alcohol and drug use, and HIV-risk behaviors.

One of Gerbert's current studies tests whether interactive video—where an actor plays a doctor and a computer generates certain scripted responses based on patient answers—can effectively identify risk factors in individuals and deliver preventive interventions. With so much demanded of providers, there may be better ways, or at least supplemental ways, to help patients change their risky behaviors than direct intervention by the doctor.



Gerbert has already completed a study that demonstrated the technology's potential to identify patients at risk for HIV/AIDS and other sexually transmitted diseases. Now, she and her colleagues have created a program that analyzes respondents' answers to questions on a whole array of risk-related behaviors and suggests interventions to help modify their behavior. Should the program prove successful, it could be a powerful new tool in preventive health education.

Morton Lieberman is a psychologist who also believes that IT could supplement the efforts of health care providers, particularly in creating support communities for patients. Such communities are significant, as a number of studies connect support groups' ability to reduce stress to longer lives and improved quality of life. But there is little information about whether an Internet community can provide effective support.

Consequently, Lieberman is directing a large study involving UCSF, Stanford, The Wellness Community, and SeniorNet that will help provide that information. For his part, Lieberman is helping create facilitated Internet chat rooms for seniors with breast cancer. He notes that seniors often do not seek support, particularly in rural areas where access to such groups may be limited. The Web may be a way to give them that access. Based on exit interviews from the study's pilot, Lieberman says, "Though some people will still

need face-to-face contact, I am convinced that others can find real and supportive psychological relationships."

miriam Kuppermann and Laura Esserman are interested in the use of technology to support patient decision making. Both note the important role of personal values and attitudes on use of diagnostic testing and choice of treatments. With their colleagues, they have designed decision-making tools to clarify the patient's personal preferences while systematically considering treatment options.

Esserman's software program aims to provide support to breast cancer patients and empowers these patients to make informed decisions about their own care.

"Things happen when people get a cancer diagnosis," says Esserman.

"People get confused and overwhelmed with advice. And in many cases, the differences between interventions is marginal, so the best decision is the one that reflects these women's individual values."

In its current phase of development, this tool asks the physician to fill in patient preferences and values. Then doctor and patient study the results together. Esserman is already working on turning this structure into an interactive tool that patients can use on their own.

Kuppermann's interactive IT tool supports patient decision making related to prenatal testing. This program

begins with an overview of testing to inform women of the alternatives and their advantages and limitations. By gathering specific patient data, the tool then presents the risks involved for this individual in carrying the baby to term, as well as the risks involved with the various pre-natal tests. Finally, by answering a series of values clarification questions and exploring the various options, the woman can decide on a strategy that is consistent with her own preferences and values. Kuppermann begins testing her tool this year.

"This is part of a revolution in health care," she observes. "High-quality decisions demand a respect for both the best available scientific information and the preferences of the individual patient."

to provide the best care for their patients, providers need up-to-date information that supports clinical decisions. The demands of their job—including a crushing paperwork load—can work against getting that information. CHC researchers are examining and developing ways that IT can address these problems.

Connecting Health Care's Stakeholders

Perhaps the hottest mainstream health topic these days is prescription drugs. This is not only because people are

“The issue of disseminating useful clinical information to physicians is of fundamental importance. It implies an intersection of medical informatics and health services research that is largely untapped.”

CHC researchers:

— Break down the barriers to more informed clinical decisions and administrative efficiency in providers' offices

— Bring clinical findings more quickly and reliably to the point of care

concerned about soaring costs, but also because recent reports indicate disturbing levels of adverse drug reactions and medical mistakes related to prescription drugs. All of health care's stakeholders would surely welcome tools that could bring down costs and cut down on medical errors. According to social scientist Helene Lipton, "E-prescribing is a promising start."

Lipton is principal investigator on a Robert Wood Johnson Foundation-funded study that examines the implications of e-prescribing devices, such as Palm Pilots encoded with formularies. This exploratory study will describe and analyze the effects of these devices on the prescribing behaviors of physicians and dispens-

ing activities of pharmacists. Lipton hopes it will also predict the impact of the growing e-prescribing industry on patients, purchasers, and insurers. To accomplish these goals, Lipton explores some intriguing questions. For example, who is creating the formularies? What incentives are needed to foster better prescribing practices? How can physicians be convinced to use the technology?

Electronic medical records (EMRs) are another technological innovation that some have hailed as a way to improve care and wring costs out of the system through heightened efficiency. According to economist Robert Miller, "If you can digitize parts of a physician's work, there seems ample evidence that quality of care can improve." Yet Miller notes that only about 5 percent of outpatient settings currently use EMR. He wants to know why. By examining a dozen large practices and a number of smaller ones, Miller and his colleagues have designed a Robert Wood Johnson Foundation-funded study to uncover the costs and benefits of EMR, as well as the barriers to its adoption.

If Miller's findings can help move EMRs more quickly and securely into practice that would be a powerful complement to the efforts of Lisa Bero and Ida Sim to make usable and credible medical information more accessible to providers.

Bringing Clinical Studies to the Point of Care

Bero is co-director of the San Francisco Cochrane Center at UCSF that helps to publish the Cochrane Library. The Library is not a brick and mortar building, but an electronic collection of systematic reviews that subscribers can read via Web-based subscriptions. It is an outgrowth of the Cochrane Collaboration, a group of researchers dedicated to preparing, maintaining, and disseminating high-quality, frequently updated systematic reviews of important health care studies. Cochrane systematic reviews must not only undergo rigorous electronic peer review, but must also be updated periodically—a commitment Cochrane authors must make.

This addresses a fundamental problem with so many paper-based systematic reviews: by the time they are published, new studies have rendered their information only partially useful and partially valid.

One possible application for Cochrane is to integrate its data into information systems that could deliver it quickly to physicians at the point of care. Given the billions spent on clinical research each year—and the often disturbing lags in getting clearly effective treatments into practice—such an initiative

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seems essential for improved health. In addition, the Cochrane Collaboration has created a Consumer Network, which writes lay abstracts of the reviews; consequently, patients too

earned Sim, who is both a general internist and a PhD in medical informatics, a United States Presidential Early Career Award for Scientists and Engineers.) At the Trial Bank,

will test the value of this idea, work collaboratively to create standards, and then find a way to create an "open" electronic architecture that will enable the information to be available through

“At the Trial Bank, researchers can fully leverage the advantages of IT by gaining direct electronic access to important trial information that paper versions...could not possibly include.”

could view the information and, therefore, be active and informed participants in the decisions about their care.

Ida Sim's work could complete the circuit. One of the difficulties in creating systematic reviews and meta-analyses is that the published studies do not always contain all the data that systematic reviewers need. With this in mind, Sim has created what she calls the Trial Bank. (The Trial Bank's creation

researchers can fully leverage the advantages of IT by gaining direct electronic access to important trial information that paper versions of the trial reports could not possibly include, due to space considerations. Currently, Sim is working with both JAMA and the Annals of Internal Medicine to encourage authors to enter their trials into the Trial Bank. The initiative is part of an NIH funded study, in which Sim

any Web browser or directly through the Internet.

“The issue of disseminating useful clinical information to physicians is of fundamental importance,” says Sim. “It implies an intersection of medical informatics and health services research that is largely untapped. This presents the CHC with an enormous opportunity to fill in important gaps in our knowledge.”

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