From the Director

The Center for Health and Community was founded on the belief - rooted in strong scientific evidence - that health is determined not just by biological processes, but by people's emotions, behaviors, and social relationships. In the years since our founding, the evidence has grown. It has demonstrated with increasing clarity and specificity that psychological and social problems often play a central role in disease onset, undermine efforts to manage illness and recovery, and negatively affect quality of life.

Despite this evidence, our health care system continues to focus disproportionately on technology aimed at biological processes gone awry. No one disputes the importance of new drugs and new surgeries, but far too often the psychosocial determinants of health are ignored, dismissed as soft science, or viewed as ancillary to care.

The problems with a strictly biomedical approach were made vivid to me recently when I had the privilege of chairing an Institute of Medicine (IOM) committee examining psychosocial services for cancer patients and their families. Those services include everything from transportation and financial planning to psychological counseling and support groups. In writing our report, I spoke and worked closely with distinguished cancer providers and researchers across the country, as well as with many patients.

In numerous ways, the discussions were heartening. Not only did we find that there were many support services available, but we were able to develop a shared vision that articulates a standard for incorporating psychosocial health services into oncology care. That is a significant step forward, because it provides a touchstone - a common framework - around which everyone concerned about the quality of cancer care can gather to synchronize their efforts.

Nevertheless, while working on our report it also became painfully apparent that too many patients cannot or do not take advantage of available services. The reasons range from financial, cultural, or linguistic barriers to the failure of oncology providers or health care payers to help patients recognize the importance of psychosocial support.
Connecting Patients with Services

Despite advances in detection and treatment, a cancer diagnosis still means coming to terms with a chronic, life-threatening disease. In response, many cancer patients find themselves depressed and anxious, struggling to function normally at home and at work — and to stay on top of managing their disease. Financial, logistical, and cultural barriers to accessing care can exacerbate such problems.

As the Institute of Medicine (IOM) report on meeting the psychosocial needs of cancer patients indicates, proven options for addressing psychosocial concerns exist, but too often they are not used. Busy providers fail to mention them, insurers don’t cover them, and patients don’t find them. According to the IOM report, there is a pressing need to connect existing services to the cancer patients who need them most.

Innovation at San Francisco General Hospital

At San Francisco General Hospital (SFGH), most patients are from underserved communities whose options are limited to the services of a public health system that struggles to provide basic care. Psychosocial support for cancer patients, if available at all, can be difficult to access. To address this challenge, CHC researcher Rena Pasick and her team — in conjunction with National Cancer Institute’s Cancer Information Service (CIS) — have developed and are pilot testing an intervention that immediately connects newly diagnosed cancer patients at SFGH to the important services and information the CIS provides.

In fact, the National Cancer Institute created the CIS so cancer patients, their families, and health professionals can obtain the latest and most accurate cancer information. Patients can access the free service by calling an 800 number or through live online chat, but often lay people are unaware of the service or struggle to understand answers coming from experts trained to speak in technical terms. “Our questions are: how can we put this wonderful resource into the hands of these people and tailor the service to their needs?” says Pasick.

The initial answer is Pasick’s CIS-Link project, which brings the CIS directly to the cancer ward at SFGH in the form of an interactive kiosk surrounded by multilingual posters and flyers that help people find it immediately upon leaving their provider’s office.

The product of extensive research, the kiosk contains a simple, text-free touch screen, where people can choose videos from a multicultural, multilingual mix of people telling stories about their cancer and then prompting the newly diagnosed patient to call CIS using the phone in the kiosk. Upon picking up the phone — no dialing necessary — patients connect directly to specially trained CIS staff who not only help people find local support services, but help them formulate questions to ask their provider. Patients can take the questions to their next appointment and ask their physician to provide written answers. The patient can then return to the kiosk or call the study line from any phone and discuss the physician’s answers with the same person they spoke with on the first call, with whom they have begun to build a trusting relationship.

“During the pilot, we will be looking for things like usability, people’s comprehension, and people’s anxiety levels about using the kiosk,” says Pasick. Based on their findings, they will further hone the intervention and, later, subject it to a larger trial of its effectiveness.

Demystifying Services at the Cancer Center

Sociologist Dan Dohan is a CHC researcher who, like Pasick, is affiliated with the UCSF Comprehensive Cancer Center. “Cancer care requires a tremendous number of follow-up steps,” he says. “If you are not educated about the process, a difficult time can become even more difficult.”
“We need to make the associated services sustainable, not just an add-on to providers’ work.”

Certainly, the center recognizes this and offers an extensive program of psychosocial support services that includes: 1) an innovative decision support program that helps patients make difficult decisions about their care. (See the section on “Providing Support” below); 2) psycho-oncology services that use a psychologist or psychiatrist and/or complementary services to help people develop coping skills and work through depression and anxiety; 3) an active symptom management program that includes pain management through traditional western treatments and integrative medicine; 4) a resource center that connects people with a range of support groups and creative outlets, and; 5) traditional social work services, such as financial counseling or transportation help.

Nevertheless, says Dohan, “We understand anecdotally that our services are not used as well as they might be.” Hoping to change that, Dohan and a team are designing an intervention that seeks to properly orient all newly diagnosed patients to the services the center offers and to their likely course of treatment.

The initial design involves giving a brief, small-group orientation to all newly diagnosed patients, covering such things as who the patients can call for a particular need, where to go for specific services, when to use services, and descriptions of the various treatments appropriate to their illness. In addition to the inherent value of these sessions they will help identify patients who face language, logistical, and cultural barriers. Those patients may get follow-up help, such as an assigned patient navigator (patient navigators help people access the healthcare system and overcome barriers to quality care).

“One key question that we hope the pilot can answer is whether we need to give a specific person a job as a patient navigator or just need to redo our system to make it easier for people to navigate,” says Dohan, whose prior work focused on the use of translators and patient navigators.

Providing Support

One way to improve the effectiveness of services is to assure that patients make decisions regarding their care based on valid information and well-considered preferences. This can help patients successfully adapt to the turn their lives have taken, something the recommendations in the IOM report were designed to address.

Improving Decision-Making

Too often with cancer, patients are overwhelmed by their diagnosis and may not be able to remember crucial information or to ask about issues of concern to them. Recognizing this, Laura Esserman, director of the Breast Care Center and Jeff Belkora, a decision scientist who directs the center’s Decision Services group, have made supporting patients through these initial encounters a unique piece of what the Breast Care Center offers.

But Dohan also acknowledges that in the US, attending to the whole patient does not always pay the bills. “We need to make the associated services sustainable, not just an add-on to providers’ work,” he says. “If there’s no reimbursement, then these services need to have strategic value...that is, they need to enable us to see more patients or do a better job clinically.”

Dan Dohan
questions they asked and answers they received.

Measuring the Value of the Service

To assess whether what they offer is truly helpful, Belkora and his staff have measured its value in a number of ways. The first is by measuring reductions in “decisional conflict,” a term for the degree to which patients feel stuck or confused about a decision.

“It’s appropriate for patients to be quite stuck at the beginning of the process, but by the time they make their decision, the conflict should go down so they can move forward with some confidence,” says Belkora. Last year Belkora and his staff found their service reduced decisional conflict for breast cancer patients by 20 percent.

Second, Belkora assesses the degree to which decision services improved self-efficacy: the patient’s confidence in their ability to make strong decisions. Third, the team is measuring decision quality. “Knowledge and value measures are the twin pillars of decision quality,” says Belkora.

Knowledge implies that patients have a reasonable understanding of the known treatment risks and benefits. “We test this through pop quizzes, based on up to ten well-established facts about the care,” says Belkora. “For example: Do patients understand the survival rates of the various options?” Last year, the service increased patient knowledge by 33 percent.

Patient values are harder to measure, but are tremendously important, especially when one considers the way some breast cancer centers market their services. “The current trend at some centers to tout breast conservation rates without knowing if that is something patients value — or recognizing that some patients would have been better off with a mastectomy — may not be a true measure of quality,” says Belkora. Consequently, Decision Services is part of a multi-center effort to validate survey questions that help patients clarify which treatments best match their own values.

Community-Based Approaches

Of course, most cancer patients receive their treatment in community practices. That is why, as part of its mission, Decision Services holds public workshops with patient communities and health care professionals to help the former become better consumers of healthcare and the latter become better at serving their needs. The group is also developing software to help physicians better share treatment information with patients.

Finally, the group is bringing its approach to other communities, and is particularly gratified by the results it has seen among rural cancer patients in Mendocino County. “Despite some concerns that it wouldn’t translate well, the rural community (including significant numbers of Latino and Native American patients) has really endorsed what we do as culturally appropriate,” says Belkora.

Support in the Community

Círculo de Vida is a small, San Francisco-based community provider that also delivers crucial psychosocial support services. Founded in 1992, the group was the first successful Spanish-language cancer support group program in the greater Bay Area.

CHC researcher Anna Naples-Springer first encountered Círculo de Vida’s Executive Director Carmen Ortiz while working on a program to promote cancer screening among Latinos. “We began to wonder why certain Latina women came to support groups and others didn’t — and why these groups are comparably underused by the Latina community,” says Naples-Springer.

Together, they conducted two studies to explore their questions. One identified the barriers, benefits, and components of an effective peer support intervention for Spanish-speaking Latinas. It found that such groups should: begin close to diagnosis; build self-care skills; be culturally competent and emotionally supportive; provide cancer information; encourage self-expression; and address lack of access to and knowledge of services. The
second study found that creation of culturally and linguistically appropriate support groups for breast cancer survivors – and increasing awareness of these groups among oncologists, patients, and family members – could increase their use.

This second finding is especially important, because of how difficult many Latinas find it to ask for support in managing their cancer treatment. “Culturally, they’re not comfortable focusing on their own health; they’re used to putting their own needs after those of their family,” says Naples-Springer. “Also, it’s not easy for these women to question their physician, since so many believe their health is in God’s or their physician’s hands – not theirs.”

Using the findings from their studies, Naples-Springer and Ortiz have proposed a randomized trial of three groups of breast cancer patients. The first would get “usual care.” The second would receive peer emotional support from Círculo de Vida’s Las Angelitas, who are trained community health workers (promotoras). The third group, in addition to support from Las Angelitas, would also receive cognitive-behavioral skill building – including skills needed to identify resources to help with transportation or housework while they are undergoing therapy or to better express their needs to their spouse.

Naples-Springer hopes the IOM report can spawn more such interventions. By using cancer survivors to deliver support in community settings, the services become more accessible and more affordable. “Too many patients don’t see psychosocial support as part of the continuum of care,” says Naples-Springer. “I hope the report will have its biggest impact on oncologists and other caregivers so they will make people aware of the need for and availability of these services.”

Using the Internet

Psychologist Mort Lieberman notes that the Internet provides yet another venue for extending support to cancer patients. After a fifty-year academic career largely spent researching therapeutic, self-help, and encounter groups, it’s not surprising that the growth of online support groups would capture his attention.

It is surprising, however, that he is among a very small group of academics examining the phenomenon, especially when one considers that a 2003 Pew Internet and American Life Project noted that by December 2002, about 63 million Americans had visited a Web site that provides information or support for people interested in a specific medical condition or personal situation. “On Yahoo alone, I counted 37,500 separate bulletin board support groups for diseases,” says Lieberman.

While studying the efficacy of face-to-face breast cancer support groups, Lieberman recognized this growing interest in using the Internet for support. He embarked on a program to analyze whether these online groups are effective and to characterize how they work. Much of this research has been done in cooperation with The Wellness Community Center.

The work applies many of the same quality-of-life measures that Lieberman has used in past research on face-to-face groups. In the case of breast cancer, for example, he studies the groups’ ability to help alleviate depression or cause participants to be less burdened by their pain. These qualitative studies indicate a number of potential advantages in online groups. One study on breast cancer support groups found participants felt more comfortable expressing anger online than face-to-face – and expressing anger is often an important piece of successfully reducing stress. Other studies Lieberman has completed found that people liked the way the Internet gives them more control over timing of their support.

“It’s also cheaper,” says Lieberman, “plus many people don’t have an option for face-to-face. We think that might be behind some of the data that show more and more elderly people are using the Internet for these groups.”

In addition, because the self-directed online groups tend to encourage “lurking,” people can shop around more easily for groups that fit their needs. “Effective sub-groups tend

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Prevention and Survivorship

Of course, at a time when people have begun to better understand risk factors for cancer, the Holy Grail is still preventing the disease’s occurrence altogether.

Early Risk Factors for Breast Cancer

Prevention is certainly on the mind of epidemiologists Bob Hiatt, Irene Yen, and Dejana Braithwaite, psychologist Julianna Deardorff, and Robert Wood Johnson Health and Society Scholar David Rehkopf. All are working on different pieces of a large study that examines the role of the environment on breast development and breast cancer later in life. Hiatt leads the center, which is one of four nationwide funded by the National Institute of Environmental Health Science and the National Cancer Institute.

The project follows 444 girls (ages 7-12) in the Bay Area over five years to determine the effect of things like diet, exercise, psychosocial factors, and various environmental factors on the girls’ physical development, particularly the onset of breast development and menarche, which are important markers of the onset of puberty. Earlier onset of puberty puts young women at a greater risk for developing breast cancer later in life and girls who are overweight or obese tend to go through puberty earlier. Overweight girls also are more likely to be overweight as adults, which independently of early onset of puberty increases the risk of breast cancer.

“There are a lot of pieces of the puzzle that we’re looking at,” says Hiatt. “For example, we know there are factors in the environment – like chemicals in plastics and toys – that may affect metabolic pathways and lead to earlier puberty. The rapidly developing breast may also be more susceptible to DNA damage that could lead to subsequent breast cancer.”

Another piece of the study looks at socioeconomic status and home environment. “There is some research to suggest that when girls are raised in a family where the biological father is absent, they may go through menarche earlier,” says Hiatt. “The explanation for this phenomenon is not well understood, but it may have some evolutionary purpose, wherein girls who are no longer under the protection of a biologic male react by getting ready to reproduce.”

The study is unique, partly because of its scope and depth, but also because of the level of community involvement. “Community members bring us their concerns, let us know what they want us to be aware of, and help us communicate back to the public and participating families,” says Hiatt.

Yen joined the project in 2006 when she became one of 53 researchers statewide to receive a grant from the California Breast Cancer Research Program to study the impact of urban planning.
“We believe every new or metastatic patient should talk to a psychologist – we expect they will need these services, that it should be routine.”

Irene Yen

policies and the conditions of neighborhoods and their services on girls’ exercise and eating habits. Her work piggybacks on the larger study.

“My interest is in the connection between neighborhoods and obesity,” says Yen. Using surveys of the girls and their caregivers – as well as neighborhood observations – Yen and her group are trying to determine how the neighborhood affects what these girls eat and their physical activity levels.

“We have a lot of information on the girls, their exercise, their weight and growth, where their caregivers shop for food...now we need to determine whether there is a connection between these and how their neighborhoods are organized,” says Yen.

To amplify that information, Yen is also using a Hellman Early Career Award from UCSF to link the Kaiser girls to another database: the Our Space GIS database, being built by CHC public health nutritionist Barbara Laraia for fourteen counties in northern California. The database will contain information on things like grocery stores, fast food, and open space. “The database will enable a deeper understanding, because we can quickly calculate things like how easy it is for the girls and their families to get to a fast food place as opposed to the grocery store,” says Yen.

“These two grants provide an unusually rich array of neighborhood information,” Yen continues. She hopes that these concentric circles of information – data from the girls and their caregivers, neighborhood observations, and the GIS database – will yield insights that can ultimately better inform neighborhood planning efforts. “Beyond this project, we’re interested in working with city planners to understand the health relevance of economic development programs – this is really a growing edge for public health.”

The Challenge of Implementing the IOM’s Recommendations

Prevention should make an enormous difference but cannot yet completely eliminate cancer. And as the IOM report makes clear, with more and more people surviving a cancer diagnosis, survivors need more than medical technology to meet their needs.

“The whole idea of survivorship is that during or after the completion of therapy – when patients are often very tired and very scared – they tend to feel as though they’re on their own...so we take a systems approach, looking at symptoms, side effects, family, and transition to living life again,” says Esserman, of the Breast Care Center.

She notes that the IOM report reflects some positive change in this regard; in particular, some insurers are beginning to reimburse for certain psychosocial support services that the Breast Care Center used to cover with philanthropic money. This, however, is a two-edged sword. “Now that it’s a covered benefit, you need preauthorization and have to negotiate a complex infrastructure just to get people the care they need...it’s a good reflection of how difficult it is to deliver care in this system,” says Laura Esserman. Under these circumstances, patients take advantage of what the center has available far less often than they used to.

“We believe every new or metastatic patient should talk to a psychologist – we expect they will need these services, that it should be routine,” says Esserman. “That’s a powerful and important message that’s been undermined by having to preauthorize and justify a need.”

For the moment, she is working with insurers to find ways to bypass some of the preauthorization steps and, when necessary, continuing to draw on philanthropic money to offer the services. However, not all providers will have those options. This means that until the IOM’s recommendations change policies, providers will have to economically justify psychosocial support services in other ways. From Esserman’s perspective, that means demonstrating a value for the institution that goes beyond reimbursement.

“I do think if you have strong psychosocial support services, it’s a smart investment by any institution,” she says. “It reduces the number of calls, there’s less anxiety for both patients and staff, and medical staff has more time to deal with other issues and concerns...besides you can’t put a price on patients feeling more comfortable.”
This is a genuine human tragedy. Over 40 percent of Americans and their families have or one day will come face-to-face with a cancer diagnosis; there are very few among us who have not been touched in some way by this disease. With those numbers in mind, consider the effect on your life if cancer is detected too late because the system fails to get out effective messages about available and appropriate testing. Consider the challenge of quickly educating yourself about treatment choices as you and your family are reeling from the initial diagnosis. Or consider the effect on care if you can’t find transportation to your regular chemotherapy appointment or if you or a loved one sinks into an understandable depression, and so chooses to discontinue a promising treatment.

These are the very real health concerns that psychosocial services seek to resolve. As this issue of Exchange demonstrates, they are concerns that CHC researchers are playing a prominent and important role in addressing. Rena Pasick and Dan Dohan are finding new ways to make sure all patients find and use the psychosocial support services they need. Jeff Belkora, Anna Napoles-Springer, and Mort Lieberman are creating and testing innovative and culturally sensitive ways to design support services that meet the needs of a wide range of populations. Bob Hiatt and Irene Yen are looking at prevention, providing insights into the modifiable environmental factors that can play a role in cancer development. And Laura Esserman, at the UCSF Cancer Center is exploring new ways to implement the IOM’s recommendations so her patients continue to receive the support they need.

UCSF has been a leader in this domain. I am proud that our researchers were doing their work even before the IOM report came out. It is now my hope that the report will not only raise the levels of support and awareness for the work they and their colleagues across the country are doing, but that it will also be another step in helping us better prevent and manage illness of all kinds.

Recognizing the central role of emotions, behaviors, and social environments for health is an indispensable part of moving forward. ■

Nancy Adler