Eliminating Breast Cancer Health Disparities: Communicating to At-Risk Populations

A Friends of Cancer Research White Paper



Supported by The Avon Foundation for Women

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About Friends of Cancer Research

Friends of Cancer Research (*Friends*) is a cancer research think tank and advocacy organization based in Washington, DC. *Friends* is a leader in developing partnerships and advocating for policies that will get treatments and therapies to patients in the safest and quickest way possible. Working with federal health agencies, congressional leadership, academic research centers and private sector industry, *Friends* continues to create innovative educational, policy, and scientific approaches to improve health outcomes and cancer care. www.focr.org

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OVERVIEW

Breast cancer is the second leading cause of cancer death in women, but early detection, screening and prevention efforts, along with improved treatments, have resulted in a steady reduction in mortality rates since 1990. Despite this encouraging trend, troubling disparities persist between the general population and millions of women who have not benefited from widespread advances in the fight against breast cancer—nor cancer generally. Women in a number of at-risk populations—most often, members of racial and ethnic minorities, as well as those living in more remote geographic areas—tend to have less reliable access to medical information, a lack of insurance or under-insurance, a smaller number of health care professionals and oncology specialists serving their area, distrust of traditional health care institutions, and a range of socioeconomic, linguistic, and cultural barriers to seeking preventive care and treatment. These factors, combined with an increasingly complex health care providers.

In an effort to explore and address this critical public health challenge, Friends of Cancer Research (Friends), the Avon Foundation for Women, and the George Washington University assembled a panel of experts from academia, government, and advocacy for a March 2011 symposium on *Eliminating Breast Cancer Health Disparities: Communicating to At-Risk Populations*. From this discussion, the experts developed a wide-ranging set of recommendations designed to curb disparities in screening, diagnosis, and treatment for underserved groups of women. These recommendations focus on the best ways to communicate with members of at-risk populations through existing and new outlets; how to address common misconceptions that result in inferior cancer care; how to build relationships of trust and create expectations between the medical and underserved communities; and how to diversify the fields of cancer research and the health sciences as another way to improve outreach to the most vulnerable groups of patients.

Several important developments precipitated the 2011 symposium. In late 2009, the United States Preventive Services Task Force (USPSTF)—a panel of doctors and experts appointed by the U.S. Department of Health and Human Services—updated its mammography recommendations for women over the age of 50.¹ The recommendations were met with scrutiny from health care providers and patient advocates, who were divided sharply over the policy changes. Worse, the revised recommendations had caused confusion among providers and patients alike. More than two years later, the effects of the recommendations are being felt in reduced rates of screenings, particularly among women in minority and at-risk populations.

In response to the revised USPSTF guidelines, the Avon Foundation for Women conducted a survey in 48 states and the District of Columbia, the area with the highest cancer mortality rate in the United States. The results suggested a disturbing change in preventive screening patterns: In a quarter of communities surveyed, between 20 and 30 percent of women were not showing up for their mammography appointments or not scheduling appointments at all. In addition, the survey found one of the key components of mammogram screening is insurance coverage—and a lack of insurance is a huge impediment. Barely 40 percent of under- or uninsured patients were screened for breast cancer, according to the findings.

With this general state of confusion as a backdrop, the experts who convened for the *Friends of Cancer Research* symposium recognized the imperative of addressing a wide gap in public understanding, preventive services, and follow-up care. The group's final recommendations, detailed in this white paper, are aimed at cancer researchers and physicians, community health centers, advocacy organizations, government agencies, funders, and other stakeholders. Each of them has a critical role to play in addressing the national challenge to eliminate breast cancer disparities in America.

RECOMMENDATIONS

RECOMMENDATION #1: Investigate disparities between women with cancer and healthy women

The cancer research community must undertake an in-depth examination of the biological differences that exist between women with cancer and healthy women in order to identify characteristics that may be important to targeting disparities and determining treatment options.

Screening is necessary but not sufficient

The national focus on preventive screening and early detection of breast cancer is aimed, of course, at reducing the number of late-stage diagnoses and deaths from the disease. Compared to most other cancers, breast cancer has a wider margin of time during which it can be detected early—resulting in more time for more effective treatment to be administered. This advantage evades late-stage diagnosis and improves the likelihood of avoiding death. Yet these important benefits disappear if the initial screening process is not followed by affirmative next steps—which is too often the case for women who get screened but do not return for treatment or subsequent appointments.

A greater emphasis must be placed on the steps following screening, including keeping scheduled follow-up appointments and, if required, diagnoses and treatment. This task falls to a range of stakeholders in the cancer community—including physicians, community groups, and others involved in cancer prevention efforts.

One way to ensure greater continuity of care is through broader health insurance coverage. Insurance eligibility is known to significantly impact women's ability and motivation to be screened or continue care. Reinforcing the findings of the Avon Foundation study above, national surveys have shown that only 56 percent of uninsured women were likely to have had a mammogram in the past two years, while 84 percent of insured women had a mammogram.² The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) has provided subsidized screening and diagnostic services to disadvantaged women, reducing the cost and encouraging more women to screen and pursue recommended follow-up treatments. To utilize the benefits of this program, a woman needs to be below 250 percent of the federal poverty level and between the ages of 40 and 64. Under these guidelines, between 8 and 11 percent of women in the country are qualified to receive services.³ Clearly, ensuring broader access to preventive screening and services would be a valuable long-term public health goal.

Gaps in cancer incidence and mortality for at-risk women continue to widen, suggesting a range of contributing factors that must be explored

Breast cancer is location specific but is widely variable in terms of origin and treatment. Individual biological factors, often roped together by race, ethnicity, or age, may have different responses to different treatments.

A meta-analysis of breast cancer survival rates for African Americans and Caucasian shows broad disparities, even after socioeconomic differences are removed. This finding suggests that a further analysis of biological trends, genetics, and socio-cultural factors is necessary.⁴ Individual studies on the occurrence of breast cancer suggest differences in African Americans as well as biological indicators that could classify women as at-risk for breast cancer. A comparison of breast cancer death rates in African Americans and Caucasians since 1975 shows a widening gap—even as the gap between blacks and whites has narrowed for overall cancer rates. Research data shows African Americans are less likely than white women to be diagnosed in the first stage of the disease, while also having a higher chance of being diagnosed in later stages. This suggests African Americans are not being diagnosed in a timely manner relative to white patients.⁵ A similar study juxtaposed five-year survival rates against race and stage of diagnosis, and found that African Americans have a lower survival rate regardless of the stage in which they were diagnosed.

Biological disparities between some racial and ethnic groups likely explain some of the gap in incidence, treatment, and survival rates

Among the many ways to classify and group women diagnosed with breast cancer, 12 to 17 percent of women have triple-negative breast cancer, so named for its lack in expression of three receptors: estrogen receptors, progesterone receptors and human epidermal growth factor receptor type 2 (HER2). Women with triple-negative cancer are identified by not responding to typical forms of therapy and having relatively poor outcomes. Another group of patients with similar characteristics and bleak survival rates are women with basal-like breast cancer. This subtype is molecularly different and is characterized by a gene-expression profile that is similar to the epithelial layer of the normal breast. Generally speaking, these two groups of breast cancer are considered indistinguishable. They fundamentally are distinctive, but are often confused as a result of their mutually inclusive traits. Most cancers classified as basal-like render the characteristics of the triplenegative group. Conversely, some 80 percent of triple-negative cases show the same signs as the basal-like group.

Discovering the correlation between certain receptors and their outcomes has brought about great progress in breast cancer research. Not only has this helped define the biological differences between groups of women, but it has also revealed important trends in poor outcomes to certain treatments. Being able to analyze biological characteristics of breast cancer before treatment is given and deducing which kinds of treatment will or will not be effective will help optimize a range of positive outcomes. These results encourage research of the specific groups of breast cancer while also fortifying the idea that research on biological factors has been shown to be correlated with treatment responses. Further research on biological factors can help experts refine the most effective treatment for women in these populations, as well as for a broader group of women who do not share these characteristics.

If research like this identifies biological markers that suggest the probability of breast cancer and can be identified before diagnosis, it may motivate more women to begin with screening and be more attentive to their follow up, thereby catching the cancer before it advances. These bio markers should serve as a warning sign to which women are at-risk and may potentially have other characteristics as well.

A study on the histology of tumors found that the African American population had more aggressive tumors for each stage of the disease and for each tumor size above 1.0cm.⁶ Since the study was based on biological characteristics and not on statistical outcomes, it implies the function biology plays in which women are at risk. Regardless of age, for nearly all stages and grades of the cancer, African Americans were found to have lower survival rates.

The histological grade of the tumor is largely associated with the survival of breast cancer patients. This study finds that African American women are more likely to be diagnosed with a higher histological grade of cancer, an indication of poorer prognosis. The research compared African American and Caucasian women, and found that fewer white women had the lower grade, Grade I and II tumors, while African Americans had a higher relative prevalence of Grade III tumors, the most aggressive of the grades. These grades are identified by histological marker, which suggests that the disparity of breast cancer survival between races is also linked to biological factors. These evaluations imply the need to consider aspects of the apparent disparity in races that are not only social factors but also biological factors. The discovery of higher grade tumors in African American women reinforces the findings which concluded African American women were more likely to present factors like estrogen receptor-negative tumors, higher S-phase fractions, and higher mitotic activity, characteristics which are associated with more aggressive tumors and are found in higher-grade tumors.⁷

Identifying the different characteristics of these cancers, of which some are more prevalent in certain populations, will help in determining which groups need to be screened more frequently

Biological characteristics are often a sign of what the potential outcome of the diagnosis may be, and research conducted on the varying characteristics can give way to findings on more connections between them and the type of population commonly associated with them. These links and characteristics are essential to finding weaknesses in a patient's treatment and where modifications can be made. Depending on the strength, these relationships can aid in targeting women who potentially have a higher risk for cancer. Finding links between the prevalence of characteristics and associated populations will be the most beneficial in preventive screening. Moreover, researchers should rely on the substantial body of evidence that has been done to date on the biological characteristics of women in different age, race, and socioeconomic populations, and use that research to help shrink the "target zone" of women at greatest risk. The result should be more effective and accurate detection of breast cancer with early screening.

Identifying those characteristics will also help in developing targeted therapies and examining why some traditional therapies are less effective

Researching down to the biological level of the tumor will help in creating data points that can be aggregated according to how patients have responded to different types of therapy. Finding a

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common thread in those data points should help cancer researchers gain a better understanding of which kind of therapy is optimal for individual patients, and will help in predicting their reaction to the treatment. Linking biological characteristics and effective cancer therapies in this way will greatly increase the understanding of why certain therapies are less effective, and how to avoid wasting precious time and resources on those treatments with little utility.

Ultimately, all of the above research will be much more valuable if it can be compared to characteristics of women without cancer. Toward that end, the scientific community must engage healthy women to study the differences that exist in order to understand underlying differences in breast cancer prevalence. Studies have been able to group breast cancer patients according to many variables, including age, race, histology and family history, but comparisons with a control group of cancer-free women are needed to identify which of these aspects are most predictive of breast cancer. Understanding healthy women's biological make up and lifespan will create an important baseline for cancer patients, and it will yield useful data points to improve treatment and support.

RECOMMENDATION #2: Build relationships with groups that work directly with at-risk populations

Collaborations with community health centers, culturally specific groups, churches, and other public organizations can help to address barriers to screening and treatment as well as misconceptions about cancer detection and treatments that exist within at-risk populations. Among the ways to bring about needed improvements are the following.

Patient Navigator/Advocacy programs should be expanded to more hospitals that provide care to at-risk women

The growing practice of patient navigation in cancer care is a promising development that has the potential to benefit low-income and underserved populations in particular. Patient navigators (PNs) are typically non-medical professionals who build a bridge between the patient and the medical system, acting as a well-informed liaison with the patient's best interests at heart. Their key objective is to properly and efficiently manage the many steps in the patient's journey, from earliest stages of detection through diagnosis, treatment and beyond. Patient navigation is guided, in part, by the belief that having a reliable connection will encourage more patients to abide by proper protocol and follow-up care. This intermediary relationship can greatly alleviate cultural and communication disparities between the patient and physician, ease fears, and educate the patient in a more accessible and less intimidating manner. It can similarly be used as a tool to disseminate medical information that would otherwise have to be sought out by the patient. The combination of more knowledge and a reliable aide through the PN can positively influence the patient's decision-making for steps in prevention and treatment, effectively streamlining their process of care.

As patients benefit by getting simplified basic care, the health care system and public or government financing systems gain an upper-hand on early treatment, thus cutting down the incidence and cost of late-cancer care. Motivated by these and other advantages, the program has been implemented

in several states and piloted with support from the National Institutes of Health and American Cancer Society, for example.

Multiple studies have tested the advantages of having a PN involved with minorities and/or lowincome women. Generally, navigated patients show significant improvement in the adherence to efficient care management over similar patients receiving standard care. For example, a study of patients with abnormal screenings done at the National Institutes of Health compared patients offered a PN to patients who were offered standard service. Those that were assisted by a PN had an 87.5 percent fulfillment rate for recommended biopsies, compared with 56.6 percent fulfillment among those without a PN. Of those that were in the group receiving biopsies, the patients that were aided by a PN got their biopsy in considerably less time.⁸ More conclusively, the nation's initial patient navigator program, launched in 1990 at Harlem Hospital by Dr. Harold Freeman and colleagues to assist low-income and medically underserved patients, showed an increase in 5-year survival rates from 39 percent to 70 percent in only five years. The program at Harlem also found a drop in late stage cancer cases by more than a half.⁹

On the strength of the evidence, more health care providers should offer the option of a patient navigator for underserved women, especially those less likely to follow up on treatment. The approach is supported by many foundations, including the Avon Foundation for Women, which provides grants to hospitals to promote patient navigators. At a broader level, the Foundation and trained patient navigators share an agenda to not only aid underserved women going through treatment, but to also disseminate information on breast cancer screening and treatment to underserved populations. The field would benefit greatly from broader investment in this form of support for cancer patients.

Community leaders can also help tackle barriers of culture and mistrust between atrisk patients and the health care system

A physician's advice should be perceived as a trustworthy source for all patients. Yet too often, members of minority groups approach doctors—and the health care system generally—with deep skepticism and distrust. Just as patient navigators can serve as honest brokers to break down perceived barriers, trusted leaders can also become powerful advocates for breast cancer awareness within at-risk and underserved communities.

By virtue of their respected positions in the community, civic and religious leaders should be recruited to help disseminate information, advocate the strengths of the health care system, and serve as an informal link between reticent members of their community and health professionals. These community leaders can be aided with small media like pamphlets and posters as well as public discussions. Promoting community leaders to attain proper education on how to best inform patients has the potential to address not just health disparities, but also to make needy patients aware of the financial assistance they can receive.

Ultimately, building bridges like this would help make patients from at-risk communities feel more comfortable with their primary physician, would help address misconceptions about the health-care system, and would open the door to more education and reassurance about preventive tests. By taking this "bottom-up" approach, it could empower those at greatest risk of breast cancer to follow through with their physician's recommendations—saving many lives in the process.

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At-risk and underserved women must be educated by stories of success

Breast cancer awareness is a nationally known campaign that broadly showcases its cause in the media. Through various sponsors, most notably Susan G. Komen for the Cure, the campaign has raised a sense of familiarity in the public. From football teams and food products to old-fashioned poster boards, the pink ribbon of breast cancer awareness has made an impact on our collective conscience—reminding us of the importance of prevention and early detection while keeping the end goal of finding a cure for breast cancer in mind.

Despite this national awareness, however, the campaign has not permeated as successfully with some groups at greatest risk of breast cancer. There are a number of reasons for this, not least the fact that many members of underserved and minority populations remain fearful of diagnosis and treatment due to the expected financial costs and projections of an unpleasant outcome. Sadly, these outcomes have become a self-fulfilling proposition, as at-risk and underserved women make up a disproportionate share of late-stage diagnoses in breast cancer.

On its website, the Susan G. Komen organization has created a space for breast cancer survivors to write about their success stories, providing a platform of hope that can encourage women to seek treatment earlier and be less frightened of negative results. Optimistic testimonials like these are especially important for women in underserved, minority, and at-risk populations. By educating them about success stories, health advocates and other professionals could help address their fears and positively change their perception of breast cancer screening, early detection, and treatment. Doing so may also build a trust in the system working and having beneficial results. And while these stories alone cannot amend the fear of cost, they can help persuade at-risk women that the costs of doing nothing are far greater.

Similarly, physicians could dramatically help change perceptions among disadvantaged women by highlighting the benefits of early detection and clearly communicating the message of success for patients who take proactive steps to address their disease.

Closer collaboration and information sharing among the many cancer groups will serve everyone's interests

Across the field of cancer research and prevention, numerous individual organizations have done an excellent job of advocating for their particular interests and advancing their specific cause. Yet as organizations work to build their knowledge and expand their research, the strongest tool is to work with the many other organizations that have the same basic goal. Joining certain organizations that may have expertise in different aspects of cancer research, for example, will also aid in narrowing differences. Organizations are often limited financially, and even more so geographically. Pulling together the information from various institutions will help gather and relate expansive data that may otherwise not have been related. This will help align the goals of these institutions while also promoting thinking out of the box by allowing innovative solutions.

The same principle applies to reaching at-risk populations. Much of the research and information that could benefit at-risk individuals comes from elsewhere in the field, and does not always reach the community health centers or hospitals that serve needy patients. By communicating more openly

with each other, individual cancer organizations could share techniques they have found most effective in reaching their targeted population.

RECOMMENDATION #3: Create expectations for minority participation in the scientific field

If we as a society hope to address wide disparities in knowledge of and access to health care generally and breast cancer care in particular, it is important to make the nation's health care system more diverse and representative of the population at large. That goal can start with efforts to foster interest and create opportunities for minorities in scientific fields during their primary and secondary education. It should also include efforts to encourage minority involvement in clinical cancer research trials and other research initiatives.

Clinical trials must become more representative of the general population of cancer patients

Clinical trials are a large focus of clinical oncology today, and they are central to the success of cancer research. Although trials have led to significant advancements in cancer treatments, these advancements have not benefited all demographic groups equally. Too often, cancer research attracts low participation by minority populations, and that results in underrepresentation in clinical trials generally. Surveys of at-risk communities have uncovered a number of reasons for this poor participation, including a lack of information and knowledge about clinical trials in the first place, and a widespread distrust of the medical system rooted in historic mistreatment of at-risk Americans, notably African Americans.

These concerns suggest obvious areas for improvement. To increase minority participation in cancer research, educating at-risk populations about clinical trials is paramount. Community advocates need to educate people about opportunities to participate in research trials and the importance of their participation, and keep them motivated to be a continued part of the trial.

Increase the number of trial participants by building bridges between research facilities and community providers

Many research institutions are segregated from the hospitals whose patients provide a logical source of research participants. In these cases, the physicians referring their patients to clinical trials are then placing their patients' care in the hands of researchers they may never have met. A system that preserved a closer patient-physician relationship could benefit both parties. One way to realize an improved system is through a patient navigator network, as referenced above. The involvement of PNs in the early stages of clinical trial recruitment could instill trust in more patients—thereby increasing participation—while reassuring physicians of the process, thereby increasing the number of referrals.

Integrating patient navigators into the clinical trials recruitment process would help address disparities and promote diversity

As discussed earlier, the patient navigator program has enhanced the process of creating trusting relationships with patients to augment their adherence to effective care. Patient navigators also serve as a vital channel of communication to at-risk populations, and the relationships they develop can be used to increase participation of minority patients in clinical research. Involving patient navigators in the recruitment process will increase the number of patients aware of clinical trials that may be relevant to them, and patients who are introduced to the idea in a more comfortable setting are more likely to agree to participate.

However, adding the promotion of clinical trials to the patient navigator's scope of duties must be carefully executed so as to not harm the primary goal of the patient navigator system. The patient navigators need to be fully informed of what they are promoting. Encouraging them to be involved will give them a sturdier perspective to portray to their patients and will reflect well in how the patients respond to their recruitment.

For patient navigators to be effective advocates for their clients' needs, it is also important that they be culturally compatible and able to speak the patient's language. Clear communication and cultural familiarity are critically important if the PN is to play a role in recruiting diverse patients for clinical trials, and in helping them understand the potential benefits of participation, basic disclosure forms, and adherence to trial instructions. In each of these and other areas, the patient navigator can be a significant factor in whether or not participants get the most effective personalized treatment and care.

Analyze the entire clinical trial system and ask questions about how it is organized and whether it is optimized to include recruitment

In general, the recruitment system for clinical cancer trials today is in great need of improvement. Reforms are needed to ensure that more—and more diverse—patients may be recruited for participation, while at the same time protecting their privacy and best interests. Evaluation of how the clinical trial system currently works will help create a baseline to discover which areas can be improved within the bounds of existing regulations. At the same time, physicians generally and oncologists in particular need a better understanding of why their help is essential in the recruitment process. Physicians should have an obligation to inform patients of potential clinical trials they are eligible for, while retaining the option of refusing referrals per their best professional judgment. The physician's opinion is important in these situations and should not be compromised, but they must also be engaged as active partners to ensure maximum dissemination of information about clinical trials.

Use technology, social media, and other innovative ways to reach out to diverse candidates eligible for clinical trials or research studies

Social media and technology platforms such as Facebook and Twitter have exponentially increased the speed at which information spreads and have sparked awareness that leads to involvement. The power of these and other tools should be harnessed in the health care arena generally, and can be used to bring about more interest and involvement of patients in clinical trials in particular. More research is needed to determine whether social networking sites can be effective in engaging young people and minorities especially, and educating them about cancer prevention, detection, and research opportunities. Ideally, further research on how to optimize the use of social media and technology will help shrink the distance between at-risk populations and health education as well.

Find ways to overcome linguistic barriers to ensure greater participation of minority patients

Language barriers can represent a major hurdle in reaching out to varied populations at risk of cancer. For obvious reasons, at-risk women with limited English proficiency will have more trouble finding a physician they can properly communicate with on their care. Language barriers can undermine the important physician-patient relationship, and can feed into the anxiety of doctor visits. Without clear communication, the patient is not fully aware of what is being done and why. S And when it comes to recruitment for clinical trials, this lack of information can leave limited-English speakers distrustful and hesitant to participate. To overcome these challenges, physicians will need to use education tools that are specific to the patient, like brochures and websites in their language. If the patient demonstrates interest in a clinical trial, it is important for the consent form to be in their language as well. And bilingual recruiters—including, as referenced previously, patient navigators who speak the native language—could greatly assist in outreach to minority patients, thereby increasing their involvement.

Encourage an interest in science, health and medical fields among minorities in grade school, high school, and college

Often, members of at-risk and minority groups face a range of barriers to entering professions in medicine, health and science. There are financial and educational challenges, to be sure, but social ones as well, with too few minority role models to influence a young person's decision to pursue a career in the sciences.

To address these challenges, intervention early in education is important. Creating interest at a young age can help promote minority participation in health, medicine, and the sciences, and build a "pipeline" to programs that lead to rewarding careers. And using the public school system is one important way to introduce these fields and pique interest in young people.

Educators, hospital administrators, and public health officials should take advantage of public service and volunteering requirements for high-school and college students to expose them to fields in health and science. For example, schools and local hospitals can collaborate to create or expand interesting volunteer opportunities that will help increase the number of minority students introduced to medical careers, while serving a critical community need at the same time. Similarly, the need for language translators can be fulfilled and can be further built into a career as a patient navigator. Expanding career-exploration programs like these, using job assurance as an incentive, will benefit both young people and providers, and will help diversify the science and medical fields in the long term.

Support federal mentorship programs and debt forgiveness programs which could encourage more people, including minorities, to pursue careers in health and science

The high cost of an education in medicine or health care can be a burden for many students—but it becomes an insurmountable obstacle for many young people from low-income or minority communities. Policymakers should explore and support programs like federal debt forgiveness for students who pursue health careers and agree to put their skills to use by serving needy patients in poor urban or rural areas. Similarly, they should consider expanding investments in mentoring,

apprenticeship, and other programs designed to draw nontraditional students into the fields of health and science, and to support them once they get there. Where programs like these do exist, it is also important to publicize them aggressively to minority students, faculty, and advisors so they can be fully utilized. The ultimate goal is to attract a skilled and diverse workforce of physicians, researchers, and health and science professionals that better mirrors the at-risk population in need of services.

RECOMMENDATION #4: Use current and emerging technologies to engage a larger number of patients

Across society, dramatic advances in technology have benefited health care on all levels. Most obviously, new technologies have improved the quality of care for patients and the range of diagnostic and treatment options for providers. Beyond these, though, new technologies have broken down communication barriers and barriers between cultures, making it possible to reach a worldwide audience of health care consumers and others not currently receiving adequate care. To further reduce disparities for at-risk patients, health advocates should leverage important technological advances in targeted communication, education, and outreach campaigns. A few specific ideas are detailed below.

Use mobile phone technology to reach at-risk audiences with personalized messages

The prevalence of cell phones today makes them a potentially powerful tool in the fight against health care disparities. Whether through text messaging, specified health applications, or even phone calls, health advocates should be using cell phones to raise awareness and to broadcast potentially life-saving information to communities that might otherwise never receive the message. More specifically, messaging about breast cancer through these communication efforts can be done in a way that is adjusted and individualized to reach women at risk. Breast cancer is a very personal disease, and the ability to recognize each group's unique fears and concerns is important in spurring prevention efforts and getting breast cancer patients the care they need.

At the start of the process of creating a strong line of communication and education is familiarizing underserved populations with the idea of combining health care with technology. Orientation must be done at a community level, with providers publicizing various options for cell phone outreach and simple steps for individuals interested in signing up.

As technology becomes more advanced, patients have the opportunity to create two-way communications with their providers, allowing information to flow from the patient to the physician as well as from physician to patient. For example, communication can come in the form of an informative text message that alerts the user of clinical trials in her area.

And while the ability to disseminate information in this manner is valuable in and of itself, small incentives would likely increase the rate of response. An offer of free cancer screening, for instance, could boost participation by at-risk members of the community, thereby benefiting both patients and providers alike.

Use technology to address linguistic barriers as well

In cases where individual patients cannot properly communicate with their physicians nor fully comprehend their health care options due to language differences, technology can also play a critical role. In many parts of the health care system, providers now offer brochures and advertisements in other languages. But technology can advance this effort by offering all forms of communication in multiple languages, thereby supplementing or even circumventing direct physician contact for patients who do not speak English.

Electronic forms have greatly improved health care efficiency and helped promote better patient relationships. Offering patients computerized forms and surveys allows them to find their comfort level and proficiently convey information to the physician as well as receive information they can process. Without a translator present there is the option of using computer programs to translate conversations.

Expand reliance on other innovative technologies to advance research, disseminate information, and promote greater engagement

Technology is used in research, social support, service delivery, and education. Organizations and the internet have developed multiple methods of presenting information in an effort to make it as easy as possible to understand health matters and become active. Through the Love/Avon Army of Women¹⁰ campaign, for instance, the Avon Foundation for Women provides webinars for women to learn about breast cancer causes and prevention, and discover a range of ways they can participate directly in the search for a cure. The webinars create a platform to ask questions and learn from the questions of others. They have lowered the anxiety of direct contact for many women while helping the foundation and wider research community learn from the diverse women who get involved. The webinars are used at a professional level as well to allow the exchange of ideas and to keep professionals updated. Using another form of technology, the foundation also encourages healthy women and breast cancer survivors of every age and ethnicity to register for research studies nationwide, with the goal of creating an "army of women ready to serve science".

CONCLUSION

The diverse panel of experts convened by Friends of Cancer Research in 2011 agreed that, in the end, all parties will need to work collaboratively to solve the problem of disparities in breast cancer diagnosis, treatment, and survival. As they sought to turn the symposium proceedings into actionable policy recommendations, they were guided in part by comments that day from U.S. Representative Debbie Wasserman Schultz, a breast cancer survivor and outspoken advocate for prevention and early detection measures. "There have been so many advances in screening and treatment of cancer," she reminded them, "but all of that is moot if women are not learning about their bodies, taking steps to reduce risk factors, and getting regular and appropriate screening."

The final recommendations detailed in this paper—learning from differences between healthy women and women with the disease; building stronger relationships with at-risk women and those closest to them; expanding interest and participation among minorities in the fields of health and science; and using the latest forms of technology to reach countless more women with life-saving information—will help build on the unprecedented advances being made each year against breast cancer. And taking action together will hasten the day when many fewer at-risk women suffer and die from a disease that is treated successfully for millions of their more affluent peers.

ENDNOTES

- ¹ The panel concluded that biennial screening is appropriate for women ages 50-74. It recommended against screening for women under age 40 and over age 75. It was undecided on the benefit of screening for most women ages 40-49, and made no recommendation for that age group. The panel noted that the decision to start screening under the age of 49 is a personal one taking into account patient context (e.g., family history) or values.
- ² http://www.cdc.gov/vitalsigns/pdf/2010-07-vitalsigns.pdf
- ³ http://www.cdc.gov/cancer/nbccedp/about.htm
- ⁴ (Newman LA, Mason J, Cote D, Vin Y, Carolin K, Bouwman D, et al. African-American ethnicity, socioeconomic status, and breast cancer survival: a meta-analysis of 14 studies involving over 10 000 African-American and 40 000 White American patients with carcinoma of the breast. Cancer 2002 ; 94 : 2844 – 54)
- ⁵ http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-027765.pdf
- ⁶ Henson DE, Chu KC, Levine PH. Histologic grade, stage, and survival in breast carcinoma: comparison of African American and Caucasian women. Cancer 2003; 98 : 908 17.
- ⁷ Henson DE, Chu KC, Levine PH. Histologic grade, stage, and survival in breast carcinoma: comparison of African American and Caucasian women. Cancer 2003; 98 : 908 – 17.
- ⁸ Battaglia TA, Roloff K, Posner MA, Freund KM ,Cancer. 2007 Jan 15;109(2 Suppl):359-67. 'Improving follow-up to abnormal breast cancer screening in an urban population. A patient navigation intervention.'
- ⁹ http://www.cancer.org/cancer/news/features/navigating-difficultwaters-the-history-of-the-patient-navigators
- ¹⁰ Love/Avon is a program of the Dr. Susan Love Research Foundation. More information is available at www.armyofwomen.org.

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