From the start of her career as a cancer nurse in the early 1970s, Dr. Marjorie Kagawa-Singer sensed that something was wrong with the approach to preventing, controlling and treating diseases, particularly in communities of color.

As an undergraduate nursing student making home visits during her public health rotation, Kagawa-Singer was struck both by how little patients knew about their disease and the contrast between the integrity they felt at home and the anonymity of being in a hospital. Her subsequent work with cancer patients, both on hospital clinical research units and in community settings as a nurse consultant to the American Cancer Society, only confirmed her resolve that more emphasis needed to be placed on prevention – efforts to keep people from ever needing hospitalization.

Kagawa-Singer was disturbed by something else she saw. “The disparities in cancer outcomes for communities of color compared to mainstream non-Hispanic white groups were glaring,” she says. When Kagawa-Singer looked into the research literature for factors that might explain these disparities, she found descriptions of various ethnic groups as fatalistic about their diagnosis and non-compliant with treatment recommendations. This didn’t resonate with her life experience, growing up in then-segregated Berkeley, CA, around communities of color.

So in 1982, Kagawa-Singer decided to go back to school, enrolling in UCLA’s Ph.D. program in anthropology – a field that allowed her to pursue a combined focus on psychophysiology and socio-cultural issues. In the 22 years since she earned her degree – the last 17 of them with a joint faculty appointment in UCLA’s School of Public Health and Asian American Studies Center – Kagawa-Singer has worked closely with communities of color on cancer-control issues ranging from prevention and early detection through survivorship,
as well as issues around palliative and end-of-life care. Her research has documented cultural differences in how diverse populations access and utilize cancer care based on their perceptions of cancer and the health care system.

The disparities in cancer outcomes that Kagawa-Singer first encountered when she was starting as a nurse are as troubling today as they were then. “You see it all along the entire care continuum,” she says. “Communities of color are less likely to get screened and to receive timely, quality care, and are more likely to experience severe pain at the end of life.”

Kagawa-Singer never bought the notion that fatalism was behind the lower utilization of cancer screening. “I see it as more of a rational response to untenable circumstances,” she says. “If you know you’re going to get substandard care, or if you can’t afford it because well-paying jobs are closed to you, why use time and money that could be spent generating resources for your family, and subjecting yourself to the inequities of care?” From the start, Kagawa-Singer’s approach has been to work closely with affected groups to understand and better address these disparities. “Coming from those communities, I know the wisdom in them,” she says.

Kagawa-Singer has put that philosophy into practice as principal investigator for the Los Angeles site of the Asian American Network for Cancer Awareness Research and Training (AANCART), the first cancer prevention and control research initiative targeting Asian Americans. To implement AANCART’s goals of reducing the cancer burden among Los Angeles-area Asian Americans through education, research and training of Asian American health workers in community cancer prevention, Kagawa-Singer formed a steering council consisting of representatives of 17 community-based organizations serving the region’s diverse Asian American population. “They have been partners since day one; we act as a resource,” she explains. “This approach has built confidence and trust in these communities, which include many immigrants who had never heard of surviving cancer before this project started.”

Kagawa-Singer also works with the Orange County Asian and Pacific Islander Community Alliance on Racial and Ethnic Approaches to Community Health. The community-based effort, funded by the Centers for Disease Control and Prevention, has successfully promoted breast and cervical cancer screening in seven monolingual Asian American and Pacific Islander populations through an approach that employs community navigators – peers who assist the mostly uninsured, non-English speaking women in everything from making and following up on appointments to providing transporta- tion and accompanying them on their screening exams. “Many of the women tell us they would never have gone unless the navigator was there with them, helping to answer their questions and communicating with the practitioners,” Kagawa-Singer says. “We have eliminated barriers, leading to thousands of women getting screened for the first time.”

Most recently, Kagawa-Singer received a major grant from the National Cancer Institute – $1.3 million – for a five-year study that will compare coping strategies and quality of life among Chinese-, Vietnamese- and Japanese-American breast cancer survivors. Twenty years ago, Kagawa-Singer applied for a smaller grant on the same topic – and was rejected. She believes her success in resurrecting the study reflects a sea change over the last two decades characterized by a greater appreciation for concepts Kagawa-Singer has promoted throughout her career. “Funders have finally recognized that the ‘one-size’ approach to health disparities doesn’t fit all – you can’t use measurement tools and strategies that are successful in the non-Hispanic white population and expect them to work equally well in communities of color,” she says.

Kagawa-Singer is also heartened by the growing number of people of color who are following her path and engaging in community-based cancer research. In the past, she says, researchers have followed a “deficit model” – focusing on what minority communities lack in comparison to the dominant European-American culture. Led by researchers from these communities, Kagawa-Singer says, the emphasis has shifted to finding a given community’s strengths and building on those strengths to improve health outcomes.

Kagawa-Singer has been instrumental in increasing the pipeline of cancer researchers from communities of color, through not only AANCART but also her leadership of the National Cancer Institute-funded Minority Training Program in Cancer Control Research, which has supported master’s-level minority students and master’s-trained professionals in pursuing a doctorate and a career in research. Indeed, the opportunity to mentor students is what continues to drive her.

“My plan had been to work in the community and ‘fight the enemy’ in academia where they were asking the wrong questions, and then I ended up in the enemy camp,” she recalls, laughing. “At first I was frustrated not to be on the front lines. But then I realized that my role was to increase the cadre of researchers who understand this approach. We now have 142 doctoral-prepared researchers and faculty from underrepresented communities across the country. That has been the greatest reward.”

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—Dr. Marjorie Kagawa-Singer