



HEALTH, CULTURE and SOCIETY

Global Health Equity and Advocacy:

The roles of international Non-governmental Organizations

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Abstract

International health equity and community empowerment are promoted through local and global collaborations with non-governmental organizations (NGO's). Civil society organizations and inter-agency partnerships assume central roles in addressing global health inequity, within the context of national health and social systems, local realities and priorities. Community health promotion through public-private collaboration by NGO's on health needs assessments and fund-raising is designed to increase support for local programs in the United States. This paper compares health promotion and advocacy roles of an international non-governmental organization in global and local arenas, based on community case studies by the author in rural Hungary and North Texas from 2009 to 2011, using ethnographic and qualitative research methods. Findings confirm the need for systematic evaluation of the effects of complex socioeconomic, political and multi-ethnic contexts, and the impacts of prevention programs and healthcare on health equity.

Keywords: Global health, health equity, non-governmental organizations

Global Health Equity and Advocacy:

The roles of international Non-governmental Organizations

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I. Introduction

International health equity and community empowerment are promoted through local and global collaborations among non-governmental organizations (NGO's) and civil society organizations (CSO's). These include non-profit and public interest or community-based organizations that have been established by citizens to improve health through interventions or advocacy for policy change². Such organizations and inter-agency partnerships play increasingly significant roles in global health governance, within the context of local realities and priorities³, and thus assume central roles in efforts to address health inequity.

The goal of global health equity has been advocated in public health and medical anthropology as a basic human right⁴, although it is an elusive goal and a continuing challenge. Human rights have been endorsed by the World Health Organization (WHO) as the foundation of public health practice, with expansion by the United Nations to include rights of children, women and youth, rights to safe water, food and environmental security, and rights to mental, physical and reproductive health⁵. To this end, the WHO Commission on Social Determinants of Health has advocated reduction of population health disparities, both within and between countries⁶.

Within the global health arena, non-governmental organizations (NGO's) have proliferated since the 1990's. For community health planning and promotion to reduce inequity, individual NGO's and inter-agency collaborations have developed and implemented local, national and international advocacy programs and public health interventions. Contributions of global public-private health partnerships to reducing diseases of poverty in developing countries have been evaluated as to their positive and negative impacts on national and local health⁷, while a code of conduct for NGO's has been proposed to increase potential for positive impacts on national health

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² Doyle, Cathal and Preeti Patel. Civil Society Organizations and Global Health Initiatives. *Social Science and Medicine* 66: 1928-1938. 2008.

³ Whiteford, Linda and Lenore Manderson, editors. *Global Health Policy, Local Realities*. Boulder, Colorado: Lynne Rienner Publishers. U.S.A. 2000.

⁴ Farmer, Paul. *Pathologies of Power: Health, Human Rights, and the New World of the Poor*. University of California Press. 2004.

⁵ Garcia, Rosalia and Mohammed Aker. Human Rights: The Foundation of Public Health Practice. *American Journal of Public Health* 90:5, 693-694, May 2000.

⁶ Schrecker, Ted, Audrey Chapman, Ronald Labonte', Roberto De Vogli. Advancing Health Equity in the Global Marketplace. *Social Science and Medicine* 71: 1520-1526. 2010.

⁷ Buse, Kent and Andrew Harmer. Seven Habits of Highly Effective Global Public-Private Health Partnerships: Practice and Potential. *Social Science and Medicine* 64: 259-271. 2007.

systems and decrease negative impacts⁸. Yet there is a growing need for comprehensive analyses that link global health assistance programs and political economy with institutional modalities and local practices⁹.

This paper compares the community health promotion and advocacy roles of an international NGO, Susan G. Komen for the Cure®, in addressing health inequity in Central Europe and the United States. The comparison is based on an observational case study of the NGO's collaboration with other international, national and regional public health and non-profit organizations and local Roma communities in rural Hungary¹⁰, and on community health needs assessments for the NGO in a North Texas metropolitan region, the location of its national headquarters in the United States¹¹.

II. Community Health Planning and Promotion: Rural Hungary

The international roles of Susan G. Komen for the Cure® in promoting global and local health equity offer an informative comparison with its roles in the United States. In Hungary, the Central European country where Nancy Brinker, the sister of Susan G. Komen, formerly served as U.S. Ambassador, a centralized system provides public health and primary care for residents in each district, as well as hospice care for terminally ill cancer patients. However, the extent of poverty, marginalization and social mobility varies among urban and rural populations. International NGO's, local non-profit health and social agencies, and public health districts collaborate with rural communities to promote health, increase access to health care, and advocate for social integration and empowerment of disadvantaged groups.

These groups include the Roma ("gypsies"), a culturally and linguistically diverse ethnic population that originally migrated from Northern India, and is currently the largest minority in the European Union. Most of the estimated 5 to 10 million Roma live in Hungary, Romania, Bulgaria, and Slovakia¹², forming about 6% of Hungary's population of 10 million¹³. Labor migration across the European Union has intensified as an international political issue, with the rise of ethnic nationalism, deportation of Roma immigrants from France to Romania, and recent efforts to restrict the open border-policy within the European Union.

Most Hungarian Roma live in relatively stable communities, despite their history of genocide during the Holocaust, contemporary social and political discrimination, local threats and incidents of violence^{14, 15}. Within the

⁸ Pfeiffer, James, et al. Strengthening Health Systems in Poor Countries: A Code of Conduct for Non-governmental Organizations. *American Journal of Public Health* 98:12, 2134-2140, December, 2008.

⁹ Srinthar, Devi and David Craig. Analysing Global Health Assistance: The Reach for Ethnographic, Institutional and Political Economic Scope. *Social Science and Medicine* 72: 1915-1920. 2011.

¹⁰ Lurie, Sue Gena. Approaches to Planning and Policies in the United States and Hungary: A Fulbright Scholar's Perspective. *APHA Community Health Planning and Policy Development Section Newsletter*. Spring: 9-11. 2010.

¹¹ Lurie, Sue Gena, Jim Stimpson, et al. *Community Profiles: Susan G. Komen for the Cure® Tarrant County Affiliate, 2009, Greater Fort Worth Affiliate, 2011, North Texas Affiliate, 2011*.

¹² Kosa, Zsigmond, et al. A Comparative Health Survey of the Inhabitants of Roma Settlements in Hungary. *American Journal of Public Health* 97:853-859, 2007.

¹³ Leitner, Attila. Roma Drag Each Other Down: Study. *Budapest Times*, December 11th 2009.

¹⁴ Balogh, Eva. The Trial begins: Serial Murders of Gypsies. *Hungarian Spectrum*. <http://esbalogh.typepad.com/hungarianspectrum/2011/03/>. Accessed 4-1-2011.

Hungarian population of over 10 million, the dominant ethnic group is identified as Magyar, of whom the majority is Roman Catholic; most of the Jewish population is in Budapest. As a result of negotiations by Hungary to enter the European Union, the World Bank, Open Society Institute and Roma NGO's began the Decade of Roma Inclusion, and the United Nations Development Program sponsored related initiatives¹⁶. Many Roma are currently unemployed, due to deindustrialization since "the change" from communism in 1989, and low educational levels. Some attend "special schools" for students with mental disabilities, behavioral problems, language or cultural differences. Most Roma speak Hungarian, and about 30% speak Roma languages. Since the 1990's, anti-Semitism and anti-Roma sentiment have increased.

In Hungary, where 80% of the population living in poverty is of Roma origin, a number of non-profit organizations sponsor programs to improve education, increase household income through micro-credit loans for small businesses, and advocate for legal rights¹⁷ (Orlay, 2010). The new conservative Prime Minister, Victor Orban, who recently served as president of the European Union, promised to develop a "Roma Policy" emphasizing education and employment to reduce migration¹⁸. The "Decade of Roma Inclusion", initiated by the Open Society Institute and World Bank in 2005 to ensure equal rights to education, housing, employment and health care, was endorsed by nine countries in Central and Eastern Europe, the Council of Europe and the United Nations Development Program¹⁹.

Socioeconomic determinants of Roma health inequity are evident, and research on health and social problems is supported by Hungary's National Public Health Program. While few studies have compared Roma health with that of the national Hungarian population, their self-reported health and life expectancy remain lower overall. Health promotion is advocated to improve poor health in Roma settlements, and many NGO's working with Roma communities focus on health education, training local people as community health workers²⁰.

The international Komen Foundation, in collaboration with the Open Society Institute Roma Initiatives and American Jewish Joint Distribution Committee, coordinates community health education and screenings for cancer and other health problems, with the Red Cross and local health and social agencies, as illustrated in the Marcia Presky "Equal Chance Against Cancer" program in 2009. Every woman aged 45-65 is eligible for breast cancer screening once in two years, but only about one-third are screened. Men and younger women with family histories of cancer also receive screening and services.

To increase participation in health screenings, a series of "Health Days" was held in small towns in rural regions; these are well-publicized by the Komen Foundation in Budapest, and local media. Of over 20 such health

¹⁵.Thorpe, Nick. Hungary Denies Roma Families Evacuated over Attack Fear. BBC News Europe. <http://www.bbc.co.uk/news/world-europe-13170583/2011/04>. Accessed 4/23/2011.

¹⁶ Kosa, Zsigmond, et al. A Comparative Health Survey of the Inhabitants of Roma Settlements in Hungary. *American Journal of Public Health* 97:853-859, 2007.

¹⁷ Orlay, Barbara. My Life as a *Kiutprogram* Field Worker - the Hungarian *Grameen*. *News: Society for Applied Anthropology* 21:2, pages 2-11. 2010.

¹⁸ Nation to Lead in Roma Policy: Prime Minister. *Budapest Times*. December 14th 2010.

¹⁹ Open Society Institute. *Roma Health Project*. http://www.miqhe_alth2010.net/. 2010.

²⁰ Kosa, Zsigmond, et al. A Comparative Health Survey of the Inhabitants of Roma Settlements in Hungary. *American Journal of Public Health* 97:853-859, 2007.

days held in 2009, three were observed by the author during a Fulbright lectureship at Semmelweis Medical University, Budapest. These were in:

- (1) (*Me'lyk'ut*) a working-class town in the southeastern (*Ba'cs-Kiskun*) region.
- (2) (*Nyiregyhaza*) an industrial town of about 100,000 people in the northeastern (*Szabolcs*) region near Ukraine and Romania, the site of a former military base, with an anti-Roma history.
- (3) (*Tizabo'*) a small, impoverished eastern Roma town, north of the city of *Szolnok* (in the *Ja'sz-Nagykun* region). In both of the latter, Roma families are largely dependent on social assistance.

For the first of the above events, the “Roma Minority Self Government” leader, liaison between the municipality and his community, coordinated with collaborating agencies and the regional Ministry of Health medical director; Roma families from this and surrounding towns participated in activities at the community center. This event was followed by health days for all local families, including non-Roma. Nurses, staff and volunteers provided free screenings for breast cancer, blood pressure, glucose, allergies, COPD (lung capacity), strength, vision tests, and health education, including family planning and HIV/AIDS. These were held in the spacious courtyard, where health education games, balloons, logo T-shirts, youth sports, food (sandwiches, bread, fruit), musical and dancing entertainment by local and national performers attracted participants. An evening meal of *goulyash* was shared with staff and volunteers.

The second health day observed followed another in a town near the Slovakian border, where a “Pink Walk” for the ethnically diverse community drew some Roma participants. This second event was held in a community center/gym, across the yard from a newly renovated, former primary school that had been converted into a social service center. A few staff had stayed overnight in the town of the former event, to assist with this one. Staff from the Roma *HumanNet*, various health agencies, and volunteers provided education and screenings for breast cancer, blood pressure, lung capacity, and allergies to local toxic plants. Pink balloons, health flyers, surveys and liquid vitamins were given out by Komen staff and volunteers demonstrated the breast self-exam on a model. Local educators offered support, and Austrian social work students were invited to observe this public-private/ non-profit collaboration, as a model to implement in their country.

Although women are referred to the city healthcare center for breast cancer screenings, Roma residents live in a segregated, marginal housing area and lack transportation; many have been unable to receive screenings as scheduled; some report discrimination. Health screenings were well-received and uneventful, except for an incident of a woman suffering a seizure; she was promptly given on-site care by a Red Cross nurse and transported to the hospital. Staff and volunteers met for a buffet meal after Roma families received lunches of *goulash*, bread and fruit. Recreational activities included face-painting, paper flower making and photographs; professional and local musicians and Roma dancers performed on stage for the audience.

The third event, held in an impoverished Roma farming village, had initially been planned in conjunction with a health day in a nearby small town. This event featured a speaker from the National Health Development Institute, a partner in the “Equal Chance” program, on Roma health and community empowerment. Some staff from health agencies, and technicians assisting with entertainment stayed overnight in the neighboring town. A large number of families participated at this site in the Cultural Center, to receive health education and screenings: breast cancer, blood pressure, glucose level, allergies, COPD (lung capacity) and vision testing. Komen and cancer society staff provided brochures on breast cancer, flyers with Roma logo, demonstrated the breast self-exam on a model and dispensed liquid vitamins. Children’s drawings of healthy fruits and vegetables adorned the walls of the main room, and families received bread and fresh fruit; staff and volunteers met later over a buffet at the mayor’s house across the street. Roma entertainers were welcomed, after the national Roma health expert’s presentation to a few interested participants, on the proportion of Roma in Hungary’s regions, their poor regional

health and life expectancy, and the “*Roma problema*” based on government document excerpts, village and home photographs of Roma. This presentation elicited emphatic questions and comments in Hungarian from several middle-aged Roma women in the audience; one asserted that health could be taken care of only after basic needs, and that no one is helping the Roma.

From observation and comparison of these rural health day events with local and regional agency staff and volunteers, they appeared effective in promoting inter-agency collaboration with Roma communities, and meeting some immediate needs of participants for health education and screening. However, the long-term impacts of such health promotion and screening programs on health equity and specific indicators, such as breast cancer morbidity and mortality, need to be systematically evaluated.

III. Community Health Planning and Promotion: United States

Community health promotion through participation in public-private collaborations for needs assessments, health screenings, educational and fund-raising events in the United States is designed both to reduce disease risk and health inequity, and to increase support for advocacy agencies and their programs. NGO’s provide organizational support and partnerships that encourage further development of community health promotion, participation and advocacy, and increase community support for local health services. In effect, they complement the fragmented national healthcare system in mobilizing support for prevention and treatment of specific health problems, such as breast cancer.

In the United States, fund-raising is a core function of NGO’s. Susan G. Komen for the Cure®, the largest non - governmental organization contributing to breast cancer research, has contributed \$610 million to national research and an additional \$1.29 million to community grants. In recent assessments of needs for breast cancer education, screening, and care in North Texas, local areas were selected for study of cancer mortality, screening and treatment, and to promote support for the organization²¹. Texas has many of the poorest counties, and the highest rate of uninsured persons, despite having cities with some of the highest household incomes in the nation.

Following the needs assessment in one North Texas County in 2009, and reorganization and merging of county Affiliates into regions by the national Susan G. Komen for the Cure® office in Dallas, community needs assessments were conducted with two regional Affiliates to develop comprehensive “profiles” for 2011: (1) Greater Fort Worth Affiliate, that began with Tarrant County Affiliate in 1992 and added Parker, Johnson and Hood counties in 2010, to serve women in outlying and rural areas; and (2) North Texas Affiliate, founded in 1991 to serve Collin, Denton, Grayson, and five adjacent rural counties.

For Tarrant, Parker, Johnson and Hood Counties, seventy-five percent of net funds support breast health programs to help uninsured or underinsured individuals receive continuous care and treatment; the remaining twenty-five percent is allocated to national cancer research initiatives. In keeping with national fund-raising goals, the Greater Fort Worth Affiliate has raised over \$17 million for breast cancer research, education, screening, and treatment. The Tarrant County Affiliate held its first Race for the Cure in 1993, rising over \$100,000 from 1,800

²¹ Lurie, Sue Gena, Jim Stimpson, et al. *Community Profiles: Susan G. Komen for the Cure® Tarrant County Affiliate, 2009, Greater Fort Worth Affiliate, 2011, North Texas Affiliate, 2011.*

participants and volunteers; the 2010 Race rose over \$1.6 million. Cancer screening and care are provided by one county health department, one public hospital, and several private hospitals and cancer centers²².

The North Texas Affiliate service area encompasses about 1700 square miles, with a total population of 1.42 million, of whom about 50% are women. Collin, Denton and Grayson counties are the 7th, 9th and 32nd largest counties in Texas (U.S. Census, 2009). Collin County comprises 53% of this area; Denton County, 39%. Grayson County which comprises about 8%, has the highest breast cancer incidence in women over age 50. Across this region, African Americans have the highest breast cancer mortality, and Hispanics have higher rates than non-Hispanic whites. The Affiliate has granted a total of over \$8 million to local organizations, and \$3 million to the Komen national office to fund research and grant programs. In 2009 and 2010, it granted \$800,000. With strong corporate support, it has grown at a rapid pace to meet needs of the population, especially over the last five years, but the economic downturn could result in serving fewer people. There is no local public hospital; county health departments and private hospitals provide care, with implications for cancer specialty care²³.

IV. Community Assessment Methods and Outcomes

Community profiles - assessments of needs for breast cancer prevention and care - were developed by local Affiliates in collaboration with public health researchers and volunteers, as mandated for review by the national NGO in 2009 and 2011. In 2009, when each Affiliate represented a county, the goal of increasing public support was an explicit factor in selecting local communities within the county for the profile. By 2011, county Affiliates had been reorganized into larger regional entities that included rural and/or urban communities, and comprehensive needs assessments were conducted.

For the community profiles, quantitative demographic and statistical data on breast cancer morbidity and mortality were compiled from public use sources and compared for each geographic area. In addition, qualitative assessments of health and social service resources and geographic “asset mapping” of healthcare facilities were complemented by exploratory qualitative research with community leaders and service providers, breast health educators and navigators, and screened cancer patients and survivors. Semi-structured individual interviews of persons in these categories were conducted in communities in each region, that were selected for high risk of breast cancer, need for health and social services, and need to increase awareness and prevention through screening. Focus groups were conducted with women aged 40-50 in selected communities, from diverse socioeconomic, racial and ethnic backgrounds. They were recruited through public health agencies, healthcare providers, community and neighborhood organizations, and from among participants in breast cancer survivor interviews²⁴. Each person participated in one interview and/or one focus group.

²² Lurie, Sue Gena, Jim Stimpson, et al. *Community Profiles: Susan G. Komen for the Cure® Greater Fort Worth Affiliate*, 2011.

²³ Lurie, Sue Gena, Jim Stimpson, et al. *Community Profiles: Susan G. Komen for the Cure® North Texas Affiliate*, 2011.

²⁴ Lurie, Sue Gena, Jim Stimpson, et al. *Community Profiles: Susan G. Komen for the Cure® Tarrant County Affiliate, 2009, Greater Fort Worth Affiliate, 2011, North Texas Affiliate, 2011.*

Based on the community profiles, comprehensive quantitative and qualitative results were analyzed to prioritize local needs for specific programs and funding priorities, for reporting to the national office. Program action plans were developed by each Affiliate for effective outreach, communication, and coordination of education and prevention with diverse socioeconomic, racial and ethnic groups. Priorities centered on enhanced collaboration with local health and social agencies, and more extensive funding of cancer screening and treatment for uninsured women in each area.

In the 2009 assessment of Tarrant County, community leaders and service providers voiced major health and social concerns for various chronic illnesses: diabetes, high blood pressure, heart attacks, Alzheimer's disease, prostate and breast cancer). Families' basic needs and economic survival were paramount, while they acknowledged the need for accessible, affordable healthcare for uninsured and self-employed women, children and elderly persons, preventive care and mammograms, transportation and social services. Breast health service providers offered mammograms at least once a year, while the county hospital served mainly Medicare and under- or uninsured patients. Screened patients received mammograms during annual physicals, or every two years. Most breast cancer survivors reported they conduct self-exams and had regular screening mammograms, although some did not. Focus groups elicited the most important health problems for women in the community: cancers; breast cancer, especially for African American women; also heart problems, diabetes and Alzheimer's disease.

Health and social needs included access to care, finding the right doctor and obtaining assistance with treatment. This included seeking help from other women who have gone through the same experience, to alleviate fear of the unknown. Most women got information from social networks and/or religious groups, as well as from Komen, Lance Armstrong Foundation, Cancer Center, primary care physicians, or health fairs. Some felt Komen should reach out to those "who are dying", in communities with high mortality rates, in addition to educating the public and raising funds through highly-publicized events such as "Race for the Cure". In particular, a "hands-on" presence and coordination with local community groups were desired to "make minority women feel cared about"²⁵.

In the 2011 regional profile of Greater Fort Worth, Hood County was found to have the high breast cancer incidence, but it also has an unknown screening rate, and a high proportion of uninsured women. Johnson and Parker Counties are underserved by cancer services, have the fewest medical resources and highest mortality rates. Tarrant County has the most culturally diverse population, and the highest number of uninsured women, despite sufficient healthcare resources, higher screening and lower breast cancer incidence and mortality rates.

For health systems analysis, the "continuum of care" was the framework for assessing gaps, barriers, health and social service options for women at each phase: screening, diagnosis, treatment, follow-up care, financial and social support. Within each county in this area, interrelated factors have potentially significant impacts on breast cancer incidence, prevalence and cancer mortality rates; care was found to vary according to women's residence and access to local assets. Given the diverse population's needs for cancer screening and treatment, this has serious implications for women's health, and action planning by the Affiliate to serve the large number of women who lack access to care.

Qualitative interview responses by community leaders, breast health service providers, educators and "navigators" in selected counties pointed to specific needs, such as funding treatment and expanding screening, socially and culturally-relevant health education. Although language barriers, fear of diagnosis, cost and lack of transportation hinder access to screening and care, patients and service providers are aware of and depend on the

²⁵ Lurie, Sue Gena, Jim Stimpson, et al. *Community Profiles: Susan G. Komen for the Cure® Tarrant County Affiliate*, 2009

Komen foundation for information and support. Women interviewed in the community confirmed the need for education on breast cancer services. They are motivated to get mammograms by friends or family members with breast cancer, and seek care when they perceive the need. Some African- American, Caucasian and Hispanic women are hindered by fear and/or social, economic, cultural and language barriers. Hispanic women tend to rely on family members for support; while they need financial and social services, they are often more aware of breast cancer screening and services than are recent Asian or Middle Eastern immigrants.

In general, breast cancer survivors perceive most healthcare providers as supportive and appreciate roles of Komen staff, local cancer centers, hospitals and clinics in referrals, treatment and financial assistance. Most survivors tend to use social support and/or religious groups, rather than cancer support groups. Stress, emotional adjustment and fear of death are problems for them, especially for those diagnosed at later stages. Women seek preventive care and nutrition for recovery; some also seek alternatives to chemotherapy. Their most difficult adjustments to diagnosis and treatment are for medical complications, and uncertain prognosis.

Women recognize the need to expand health education and assistance for screening, treatment, and coordinated patient navigation, and to increase funding. They perceive Tarrant County as having the widest range of services, and the need as greater in other counties, rural areas and smaller towns. They tend not to contact the local affiliate directly, and many are unaware of financial services; however, the role of Susan G. Komen for the Cure® in breast cancer research and awareness is widely appreciated.

Regional needs are to address the fear of cancer diagnosis and women's lack of health insurance, increase knowledge of services and financial support, in coordination with community social services and health education, and expand screening, patient navigation, and funding for treatment. Greater coordination with public health and healthcare providers and cancer care centers would enhance the adequacy of treatment and financial support. Komen could expand its presence among socially diverse social groups and collaboration with local organizations, to enhance awareness of services, and maintain its recognized role in breast cancer awareness and research²⁶.

From the 2011 profile in the North Texas region, breast cancer incidence was found to be highest in Montague County, closely followed by Collin County; Hunt County has the third lowest incidence and the highest mortality rate. Montague County is the most economically disadvantaged. Collin and Denton Counties are the most ethnically diverse, with large Hispanic/ Latino populations, lower poverty rates and higher household income. The remaining counties are similar in race and nativity: predominantly White, U.S.-born residents. Wise County has a slightly large percentage of persons without health insurance, although the rate is relatively even across North Texas, except for Collin County, with the lowest rate of uninsured residents.

Collin, Denton, Montague, Hunt, Fannin counties report a shortage of primary care physicians. Fannin and Hunt counties are substantially underserved; Collin has more hospitals and ambulatory surgery centers, albeit unevenly distributed.

The continuum of care varies by age group, residential location, occupation, and assets in each county, even though there is no statistically significant difference in percentage of women receiving mammograms across the area. Qualitative interviews with health care and community service providers, and health educators point to the importance of funding more treatment, expanding screenings, education and community awareness of services, and

²⁶ Lurie, Sue Gena, Jim Stimpson, et al. *Community Profiles: Susan G. Komen for the Cure® Greater Fort Worth Affiliate*, 2011.

increasing medical specialists. There is a perceived need to develop policies to address specific issues. Although fear of diagnosis, cost of care, transportation and language barriers hinder access, patients depend on Komen and are grateful for resources and support. Women in the community affirm the need for culturally-appropriate education on breast cancer services, and support for both younger and older women; most are aware of roles of the Affiliate, and of the need to expand health education and assistance for screening and treatment. Most seek care when they suspect cancer, but social, economic and cultural barriers, lack of transportation, fear of cancer diagnoses, language barriers and cost of care hinder access and delay treatment. While Asian women have the highest risk and lowest rate of mammograms, Komen has helped underserved women get screenings, and supports outreach seminars.

Breast cancer survivors express needs for patient navigation, specialized care, funding, and information on treatment options. Those who are diagnosed with cancer want complete information on prognosis and treatment options. Some patients must serve as advocates for themselves, to get prescribed treatments; others seek second opinions, or do their own research on new or alternative treatments. They face medical uncertainty, complications, and reconstructive surgery with the help of friends, family and support groups; stress and fear of death remain problems for many women, especially those diagnosed at later stages. Yet many value preventive care, better nutrition and physical activity, for more complete recovery.

Although Komen's services are widely recognized, and resource information is valued and shared, the continuum of care is seen as in need of enhanced funding for treatment, primary and specialty care, cancer screenings, education, and knowledge of services. Efforts to reduce breast cancer incidence and mortality in the North Texas region must begin with comprehensive community assessments of the relationship of social and demographic factors to healthcare resources, including health insurance and access to care. Reasons for the lack of statistically significant differences in the percentage of women receiving mammograms across the region need to be more fully explored, since there are wide variations among and within counties in the distribution of health facilities and local assets. The healthcare system also extends across county, regional and state boundaries, with important implications for health and support services²⁷.

These community profiles have found that advocacy roles of the NGO are generally effective in increasing public awareness and support through fund-raising and community health education programs. Regional and county assessments of health indicators, service needs, resources and perceptions among diverse local groups are valuable in identifying needs for health education, screening and treatment. However, they must be complemented by extensive evaluation of the impacts of prevention programs and healthcare services provided with their support on trends in health outcomes over time, to assess roles in reducing health disparities within local communities

V. Conclusions: Health Equity and Advocacy by Non-governmental Organizations

International non-governmental health programs that promote health equity through community and ethnic group empowerment and societal participation play an increasing role in global health governance. Their roles and effects vary with national economic development, social and political organization, and cultural context. When health education and screening are integrated through local and global collaborations, within national health systems that proffer primary care for all citizens, community empowerment and participation have the potential to reduce

²⁷ Lurie, Sue Gena, Jim Stimpson, et al. *Community Profiles: Susan G. Komen for the Cure® North Texas Affiliate*, 2011.

health disparities. Yet, complex socioeconomic and political priorities, poverty and multi-ethnic issues such as marginalization and social exclusion must also be addressed, and their impacts on health equity evaluated.

Community health promotion and planning by NGO's in the United States are designed to increase public awareness and financial support for local and national programs and services. These are typically provided by advocacy organizations dedicated to reducing the impact of a specific disease, such as breast cancer, although they are supported by inter-agency collaboration with local service providers and community groups. However, within the context of socioeconomic inequality and the fragmented healthcare system, health disparities persist among ethnic, racial and socioeconomic groups, despite the implicit goal of health equity across the population. Community health assessments of health indicators, service needs, resources and perceptions among diverse groups are valuable, and must be complemented by extensive evaluation of the impact of prevention and healthcare services on health outcomes.

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