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M. Elise Radina

University of Northern Iowa

Daniel R. Longo

University of Missouri-Columbia

Jane M. Armer

University of Missouri-Columbia

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LATINAS AND BREAST CANCER IN THE MIDWEST: FACTORS INFLUENCING SURVIVORSHIP

M. Elise Radina, Ph.D., CFLE, Daniel R. Longo, Sc.D., Jane M. Armer, Ph.D., R.N.

ABSTRACT

Latinos are the largest ethnic minority group in the U.S. and the Midwest is experiencing the fastest growth in residents of Hispanic descent. Rural health care delivery systems in these areas must therefore respond to changing demographics and provide culturally appropriate service delivery. The incidence rate of breast cancer among Latinas is lower than that among non-Hispanic women; however an increasing number of Latinas are being diagnosed with breast cancer. Despite higher mortality rates from cancer than non-Hispanic women, more Latinas are being treated for breast cancer and are now facing their own unique survivorship experiences. This paper addresses factors that may influence Latinas' breast cancer survivorship in the Midwest (e.g., risk factors such as biology, lifestyle, culturally mediated health beliefs; access to necessary cancer care in rural areas) and survey research on survivorship experiences in cultural contexts. Essential areas for future research are identified.

Latinos are the largest ethnic minority group in the United States (1) and the Midwest is experiencing the fastest growth in residents of Hispanic descent. (2,3) Many Hispanic women (Latinas) are likely to enter American's heartland as part of a growing number of migrant and farm workers. (4-6) This influx of Latino residents presents new challenges for rural health care delivery systems that must respond to changing demographics and provide culturally appropriate service delivery. (7) Although the incidence rates of breast cancer among Latinas is lower than that among non-Hispanic women, an increasing number of Latinas are being diagnosed with breast cancer. Further, Latinas have a higher mortality rate from cancer than their white, non-Hispanic and black sisters. (8,9) Despite this, more Latinas are being treated for breast cancer and are now facing their own unique survivorship experiences. (8,9) Delgado and associates suggest that research into breast cancer survivorship for Hispanics is at least five years behind studies of survival in other populations. (10) For example, while we understand menstrual and reproductive history are accepted risk factors for breast cancer in a number of racial/ethnic populations (11), we do not yet have sufficient data among Latinas to draw sound conclusions on such risk factors specific to this group. The growing Latina population in the Midwest makes it imperative that health professionals and social scientists in the rural areas of these regions better understand factors affecting risk for breast cancer, screening, diagnosis, access to treatment, and survivorship.

The purpose of this paper is to discuss factors that may influence breast cancer survivorship experiences among Latinas living in the Midwest. We discuss factors that affect Latinas' breast cancer survivorship experiences (e.g., biology, lifestyle, environment, culturally mediated health beliefs) and the societal factors that may influence access to necessary cancer care in rural areas, as well as review survey research on survivorship experiences in cultural contexts. Using this review of the literature, we identify essential areas in which additional research is needed to inform our understanding of Latinas' survivor-

ship, and consequently to help social and health service professionals in the Midwest and rural areas respond to the needs of Latina breast cancer patients/survivors and their families.

HISPANIC/LATINO POPULATIONS

Hispanic populations represent the fastest growing ethnic group in the U.S. and are deserving of increased research attention. (12) "Hispanic" refers to individuals who share origins in Spanish-speaking countries (e.g., Mexico, Cuba, Puerto Rico, El Salvador). (13) The term Latino/a is used in this paper to refer to individuals of Hispanic descent who are living in the U.S. The reason for this is that "Latino" is the ethnic label preferred by many of Hispanic descent.

The heterogeneity of the Latino population is evident in its diverse racial composition and widely-dispersed geographic origins. (14,15) Individuals of Hispanic origin currently account for 12 percent of the total U.S. population -- a 33 percent increase in the past 10 years, largely based on high levels of immigration. (16,17) Members of Latino sub-groups are comparatively younger and have a higher birth rate than the total U.S. population (18); consequently, a significant increase in the number of Latino older adults is expected in the next 50 years. For example, the population of Mexican Americans over the age of 65 is expected to be approximately six million by 2050 -- roughly 10 percent of the projected Mexican American population. And by 2050, the population of Mexican American oldest old -- those over the age of 85 -- is expected to number more than one million or approximately 2 percent. (18) With this increased age also comes increased risk for breast cancer among Latinas. (8,9)

Latino populations have historically settled in metropolitan areas of the East Coast (e.g., New York City, Miami), West Coast (e.g., Los Angeles, San Diego), and the Southwest (e.g., Phoenix, cities along the Mexico-U.S. border). (19). Not surprisingly, the majority of research involving these populations has focused on the experiences of Latino individuals and families living in urban areas. In recent years, Latinos have begun to migrate to more rural areas of the Midwest (4-6,20), often in search of employment as skilled laborers in agricultural or food producing industries. (21) This has brought new challenges to social and health service providers in these areas as they work to assist newcomers who often arrive with few resources. (7)

One outcome impacting the growing population of Latinos in the U.S. is the experience of acculturation to mainstream U.S. beliefs systems. *Acculturation* refers to the process whereby individuals from one culture adapt to the values and beliefs of another culture. (22,23) Among Latinos, acculturation to U.S. mainstream values is characterized by diminished identification with the culture of origin, loss of contact with family in the country of origin, increasing length of stay, decreased adherence to traditional cultural

¹The term "Latina" refers to Latino women. "Latino" refers to men as well as groups of individuals of Latin descent that may consist of males and females.

²The more familiar term "Hispanic" is used in the present paper when referencing research in which this term is used. This is to avoid misrepresentation of the authors' intended meaning as some may interpret the terms "Hispanic" and "Latino" to not be synonymous.

Radina et al.: Latinas and Breast Cancer in the Midwest: Factors Influencing Survival and Improved English-language Proficiency. (24) Acculturation brings the likelihood that Latinas may alter health beliefs and subsequent behaviors (e.g., breast cancer screening) in response to influences from mainstream U.S. values. (25-27). These changes, in turn, may lead to increases in longer-term, breast cancer survival rates.

BIOLOGICAL CHARACTERISTICS OF BREAST CANCER

In order to best understand the cancer experience among Latinas, it is important to first examine empirical and clinical literature regarding disease presentation and biological risk factors that may influence the incidence of breast cancer among these women.

Incidence

It is predicted that more than 200,000 persons will be diagnosed with breast cancer in the United States in 2004. (9) Some 82.6 Hispanic per 100,000 white women will be diagnosed with breast cancer (8) and these women are proportionally more likely to be diagnosed at a later stage of disease than their white, non-Hispanic counterparts. (10,28) As with other ethnic groups, breast cancer is the most common cancer women experience. Unlike other groups where lung cancer dominates mortality outcomes, breast cancer is the leading cause of cancer death among Hispanic women (17.5 per 100,000). (8\29)

While breast cancer survivorship among whites and blacks has been studied, breast cancer survivorship among white, non-Hispanic compared to Hispanic populations has not been studied in detail. (10,30) Methodological issues, such as sample sizes too small for sophisticated statistical analysis that compares Hispanic and non-Hispanic individuals, have prevented more advanced examination of factors affecting breast cancer risk (e.g., lifestyle, environmental, and biological/genetic risks), screening, diagnosis, treatment and survivorship.

Stage at Presentation

Findings from a tumor registry study of stages of diagnoses for breast and gynecological cancer (1981-1989) among blacks, non-Hispanic whites, and Hispanics in Dade County, Fla., (28) indicated that there was a significant increase over time in percentages of early stage diagnoses of breast cancer in all three groups, but the percentage of early stage diagnoses (in situ and local stage) was significantly lower among blacks and Hispanics than among non-Hispanic whites. While 58 percent of breast cancers were diagnosed at the early stage among non-Hispanic whites, only 51 percent of Hispanics and 35 percent of black cases were early stages. Thus, non-Hispanic whites were more likely to be diagnosed with breast cancer at an earlier stage than Hispanics or non-Hispanic blacks in both time periods. Among all three groups, the highest percentages of early-diagnosed cases were found among those older than 65 and the lowest percentage among those younger than 45 years.

Hedeem and White (2001) examined breast cancer tumor size and stage by ethnicity and birthplace. (31) They found that Hispanic women with breast cancer had a higher percentage of tumors that were larger than 1 cm (77.7 percent) than non-Hispanic women (70.3 percent), as well as a higher percentage of tumors greater than 2 cm in size

(45.9 percent versus 33.0 percent). Further, Hispanic women born in Latin America had higher percentages of tumors greater than 1 cm in size (82.2 percent versus 75.2 percent) and greater than 2 cm in size (54.1 percent versus 41.7 percent), as compared with U.S.-born Hispanic women. These findings suggest first-generation Latinas experience a delay in the timeliness of their cancer diagnosis.

Survival Rates

The five-year survival rate for non-Hispanic, white women with breast cancer is 85 percent while for Hispanic women it is 76 percent. (30) Delgado and colleagues examined available survival data from a large historical cohort study of 15,913 breast cancer patients diagnosed in San Francisco (five counties) and New Mexico (one county) and enrolled in the National Cancer Institute's Surveillance Epidemiology and End Results Program (SEER Program) between 1975 and 1984 (followed through 1986). (10) Findings from 14,896 patients indicated that a significantly higher proportion of Hispanic than white patients were: diagnosed under age 50, married, diagnosed at a later stage of disease, diagnosed in New Mexico, lived in areas of greater poverty, were diagnosed between 1980-1984 and died from breast cancer. (10) Univariate proportional hazards analysis revealed that: being > 50 years old, experiencing > one month delay between diagnosis and treatment, being unmarried, being diagnosed at a later disease stage, not receiving surgery, living in high poverty areas, receiving radiation and receiving hormonal treatment were associated with reduced survival time to death of any cause including those that may be unrelated to breast cancer diagnosis.

Hispanic ethnicity, along with other risk factors, was associated with reduced breast cancer survivor time. (10) When the effect of ethnicity on general and breast cancer survival time was studied while controlling for other risk factors, the analysis revealed that: being > 50 years old, being unmarried, being diagnosed at a later disease stage, having ductal carcinoma, living in high poverty areas, not receiving surgery, receiving radiation and receiving hormonal treatment were associated with reduced general survival. All these risk factors plus Hispanic ethnicity (but not age, marital status and time period of diagnosis) were associated with reduced breast cancer survival time. Poverty was a significant factor in both general and breast cancer survivor time. Ethnicity was not a significant risk factor for reduced general survival time, but was a significant factor for reduced breast cancer survival time. Further, ethnicity was not a significant risk factor for either reduced general or breast cancer survival time in young patients, but poverty was a significant risk factor for both. For older breast cancer patients (> 50 years) who are Hispanic, death from breast cancer is 1.23 times more likely than for a white non-Hispanic patient.

In a sub-analysis of 861 Hispanic patients, age, stage, surgery and hormonal treatment were significant risk factors for reduced survival time from any cause of death and for cancer specific death. (10) Poverty was not a significant factor in survival for either outcome. For younger Hispanic women (< 50; n=328), stage, surgery and delay in treatment were significant risk factors for reduced general survival time; stage, surgery were significant risk factors for reduced breast cancer survival time. For older Hispanic women (> 50; n=533), stage and surgery were significant risk factors for reduced general survival

Radina et al.: Latinas and Breast Cancer in the Midwest: Factors Influencing Survival Time; stage, surgery, hormonal treatment and diagnostic period were significant risk factors for reduced breast cancer survival time. Poverty was not a significant factor in either survival time for either age group; diagnostic period (1980-1984) was a predictor for both age groups for breast cancer survival time.

Biological Risk Factors

Gilliland, Hunt, Baumgartner et al. (1998) studied reproductive risk factors among New Mexico Hispanic (n=719) and non-Hispanic white (n=836) women with breast cancer and a matched control group obtained by random digit dialing. (11) Older age at first full-term birth (FTB) was associated with higher occurrence of breast cancer among Hispanic women (odds ratio for those age 27 and over versus those 18 or younger was 2.26, versus 1.60 among non-Hispanic white women). The effect of parity on breast cancer occurrence differed significantly ($p=0.008$) for Hispanic and non-Hispanic women. Nulliparous Hispanic women had a higher risk for breast cancer than those who had a single birth (odds ratio = 2.75), a risk not apparent for non-Hispanic women. While this study did not find increased risk in nulliparous non-Hispanic women, these findings are consistent with well-established findings that having given birth usually increases risk among women of all racial/ethnic groups. Research suggests that the long-term protection of pregnancy is associated with terminal differentiation of target cells and decreased susceptibility to neoplastic transformation by carcinogens. (32-34) Gilliland, Hunt, Baumgartner et al. suggest the effect of full-term birth on breast differentiation differs between Hispanic and non-Hispanic women. (11) Specifically, they hypothesized that the first FTB in Hispanic women produces maximal differentiation of breast tissue, with little increased effect in subsequent pregnancies, whereas multiple FTBs are required to produce maximal breast differentiation among non-Hispanic whites.

Increasing cumulative lactation duration was associated with less breast cancer risk in both groups, with a greater decrease in risk among non-Hispanic whites (odds ratio = 0.58 versus 0.78) (11) No increased risk was seen with number of spontaneous abortions for either groups, but the timing of induced abortion in relation to time of first full-term birth was significant for Hispanic women's breast cancer risk (odds ratio=2.29; $p = .046$). (Analyses were limited due to small numbers reporting induced abortions.) Contrary to established findings for diverse samples of women, age at menarche, menopausal status and age at menopause were not found to have strong influences on breast cancer risk in any group. Adjustment for parity, age at first full-term birth, and lactation duration explained approximately 17 percent of the difference in breast cancer incidence rates for women aged 50-74, but none for younger women.

Gilliland and colleagues examined the effect of physical activity on breast cancer risk in ethnic groups including Hispanic women. (35) Hispanic women with breast cancer in general were less educated, used hormonal replacement therapy less often and had lower parity than Hispanic controls without breast cancer. In general, Hispanic women had less education, had an earlier age at first full-term birth, had a higher parity, used less hormone replacement therapy, had less fibrocystic breast disease and had fewer first-degree relatives with breast cancer compared with non-Hispanic women. Fat intake and total calorie intake was higher among Hispanic women than non-Hispanic women. Hispanic

participants had a higher body mass index than non-Hispanic white participants. Hispanic women reported a higher number of physical activities and total weekly number of activities (mean = 8.6 activities/week) than did non-Hispanic white women (mean = 7.1 activities/week). Total and vigorous physical activity was greater for controls than breast cancer cases for both Hispanic women and non-Hispanic groups. High levels of vigorous physical activity were associated with substantial reductions in breast cancer risk in Hispanic women and non-Hispanic women ($p = .066$). For those who Hispanic women who engaged in vigorous activity there was a 66 percent decrease in risk of breast cancer compared to non-Hispanic women who performed no vigorous activity (40 percent decrease in risk). Thus, among Hispanic women, it appears that increasing levels of vigorous activity were associated with decreases in risk.

These studies give us insight into areas of similarity and differences in biological and lifestyle factors influencing breast cancer risk among Hispanic women and non-Hispanic women, and also point to the great need for further rigorous research examining differential risk factors in breast cancer development among ethnically/racially diverse groups.

HISPANIC/LATINO CULTURAL BELIEFS

Understanding breast cancer experiences among Latinas cannot be fully understood by examining biological and environmental risk factors alone. We must also understand the ways in which the patient factor of health beliefs influences Latinas behavior with regard to screening, treatment and survivorship.

Health Beliefs

It has been well documented (36-39) that Hispanics' cultural-mediated health beliefs may influence health behaviors within this population. Health beliefs have been found to have a direct relationship to use of cancer screening facilities, cancer-screening behaviors and use of health services in general. (40) The concepts of *marianismo*/*machismo* and spiritual beliefs that include a fatalistic attitude and an external locus of control have particular influences on the breast cancer experiences of these women including their beliefs about their cancer risk, the causes of breast cancer, and the utility of breast cancer screening.

The concepts of *marianismo*/*machismo* reflect expectations surrounding gender role differentiation within Hispanic cultural value systems. (41) According to *machismo*, the family operates in a patriarchal fashion with the male assuming responsibility for the family's material well-being. Men are expected to be strong, virile, and protective of the women in their lives. On the other hand, *marianismo* suggests that women are expected to consider their personal needs as secondary to those of the family. The responsibility for care of the home and the children is that of women. (41-42) Also, women are expected to be well-behaved and virginal. (43)

These beliefs have a profound effect on the way women approach their health with particular influence over their health behaviors related to breast cancer. First, Latinas may be less likely to seek care for their own health concerns including preventive care because it is expected that they sacrifice their own needs for those of their family. (44) Many of these women may also avoid screening for breast cancer because having breast cancer

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would inhibit a woman's ability to take care of herself or her family. (45) Second, Hispanic women may avoid seeking care related to breast cancer because of concerns about modesty and the fear of social stigma related to perceived causes. Touching or exposing one's breasts, even in the presence of a physician for the purpose of medical care, may be seen as a sexual activity and thus inappropriate behavior for Hispanic women. Research has suggested that many Hispanic women hold the belief that breast cancer is the result of some type of bad behavior (e.g., sexual activity, physical mishandling of the body, drug/alcohol use, living "wild"). (44,46-47) Thus, seeking breast cancer screening, actually being diagnosed with the disease and seeking care for breast disease may hold enough of a social stigma that these women avoid medical care for breast cancer. (44-45,48) Third, Salazar found that many Latinas cited the influence of their husbands' beliefs that doctors are taking advantage of their wives physically as a reason not to engage in breast cancer screening activities. (44)

Values associated with spirituality/religion also seem to dominate culturally-mediated health beliefs among Hispanics, which in turn impact how Hispanic women experience breast cancer. Specifically, having an external locus of control and belief in *fatalismo* combine with health behaviors (i.e., passivity and use of alternative remedies) to create unique contexts in which to experience breast cancer. Health locus of control refers to individuals' beliefs about whether they have control over their health statuses and outcomes. (49) An external locus of control exists when an individual possess beliefs that others (e.g., God, fate, physicians) are in control of her health rather than her having control over these things. Among Hispanics, it is not uncommon to maintain an external locus of control or sense of fatalism or *fatalismo*. (47,49,50) Smiley, McMillian, Johnson and Ojeda found that Hispanic women were significantly more likely than non-Hispanic white women to attribute health to chance or powerful others (e.g., God). (51) At the same time, they were also more likely to believe their health status is a matter of luck. Similarly, Borrayo and Jenkins found that many Hispanic women believed that 1) they were physical predetermined (i.e., fated) by heredity or other physical factors beyond their control to get breast cancer, 2) breast cancer was the result of some detrimental external sources also beyond their control (e.g., intake of caffeine, trauma to the breast, exposure to pesticides), 3) they were subject to divine predestination (i.e., "God's will has already determined that I will develop breast cancer."), and 4) breast cancer is a fatal illness therefore it is futile to engage in treatment strategies to prevent, heal or treat it. Hispanic women often cite these beliefs as reasons not to engage in breast cancer screening. (46,52) This lack of knowledge about the empirically-sound causes of breast cancer was common among Hispanic women from lower socioeconomic backgrounds, reflecting their often lower educational levels and lack of access to medical care and accurate information. This external lack of control is in direct contrast to the U.S. medical model that is patient-centered and based upon the belief that the patient is in control of her own health and thus is an active participant in treatment. (49) The interaction of these two belief systems may serve as a barrier to breast cancer care for Latinas.

Many traditionally-oriented Hispanics are likely to approach their health from a passive perspective. This behavior is based not only on the belief that poor health is fated but also that health care providers are extensions of God who have control over health

status. (39) This attitude toward health care may be one explanation for lower breast cancer screening rates. Thus, Hispanic women may be considered at greater risk for breast cancer because their beliefs about fate and external control make them appear less active in their care. (49) They may be less inclined to engage in traditional self-care (i.e., screening and general health maintenance behaviors) or to challenge the recommendations of health care providers.

Health care in the U.S. has historically stressed the values of white, middle-class America and has thus ignored health practices that are congruent with an individual's or family's ethno-centric health beliefs. (53) Thus, by taking the perspective of Hispanic health beliefs, we see that self-care among Latinas is not as absent as some studies suggest. Some Hispanics adhere to health beliefs that incorporate the use of home remedies, folk medicine or non-traditional/alternative therapies. (53) Several recent studies (e.g., 50,54-56) have examined the relationship between ethnicity and the use of alternative or complementary therapies. These studies have produced mixed results. The majority of findings (see 50,55-56) suggest that Latinas are more likely than non-Hispanic black and/or white women to use herbal teas, folk healers and dietary therapies. Alferi, Antoni et al. (2001) offer contradictory results arguing that, among white, black and Hispanic women, Hispanic women were less likely to pursue the use of herbal medications (i.e., teas) and spiritual healing (i.e., folk healers). (54) Clearly additional investigation into cultural differences and the use of complementary and alternative therapies is called for. In addition, no studies have been found that have specifically investigated the relationship between culturally-mediated health beliefs and the use of these alternatives to traditional biomedical approaches to breast cancer care. Researchers need to focus attention in this area.

SOCIETAL LEVEL FACTORS

Socioeconomic Status and Health Care Access

To fully understand the factors that influence health care access in the United States one must understand the historic foundations of the American health care system. From this vantage point the growth and development of the "hospital system" is particularly useful. The historian Rosemary Stevens writes ...

If pluralism is one major characteristic of the American hospital system, a second is social stratification. American hospitals have long served as vehicles for defining social class and race, and for interpreting American attitudes to indigence; in the United States, poverty means failure. Hospitals such as Philadelphia General, Bellevue, and Kings County in New York, Cook County in Chicago, and San Francisco General, imbued with the old almshouse tradition, were established as, and remain, institutions primarily for the very poor, and were associated with second-class social status and moral stigma...they continue to attract a relatively large proportion of the poorest Americans and a relatively large proportion of racial and ethnic minorities. (57, p. 9)

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It was at these public hospitals and the growing number of religious-sponsored institutions, such as Columbus in Chicago, St Joseph's Hospital (now Alexian Brothers) in St. Louis, and St. John's Hospital in Leavenworth, Kan.s, that America's poor, pioneers and immigrants sought medical care. Generally such hospitals - including northeastern counterparts - continue to be the choice of last resort for health care. Through this historic lens it can be argued that issues of health care access, as related to ethnicity and social class, emerged by 1850 (58) with the rise of religious and ethnic institutions designed to care for the medical needs of the increasing number of poor immigrants and those traveling across the Midwest in search of a better life. The hospital system that developed during the mid-19th century, Starr points out, "had no design since it was never planned, but it had a pattern because it reflected a definite system of class relations." (58, p. 171)

However, medical history in America is dominated by histories of the great hospitals that developed in urban areas -- in particular the Northeast and the largest cities of the Midwest. (58) The rural population of Midwestern states, in fact, relied on family members and local physicians to care for medical needs more so than those of the urban Northeast. Starr reports that due to road conditions, physicians of the 19th century were likely to travel no more than 10 miles from home. (58) While much has changed in the Midwest, geography, especially as it affects travel times and poor roads, continues to play a pivotal role in health care access today.

Several other factors also helped to create an environment that challenged use of health care services in the Midwest. Included on this list are the rugged individualism that characterized westward expansion; close-knit extended families; the agrarian economy; chronic shortages of physicians, nurses and other health care professional; and inadequate hospitals and clinics. These have become many of the variables that eventually were used by researchers, as "health care access" became an important area for investigation.

The first discussion of health access as a contemporary issue is found in the early 20th century proposals for national health insurance. (59) However, it was not until 1953 that the University of Chicago explicitly addressed health care access through the systematic review of data. In 1975, Aday and Andersen introduced their proposed basic framework (60) for studying the health care access concept that is "built upon and elaborated a behavioral model of determinants of families' utilization of health services." (61, p. 13) In their seminal work, Access to Medical Care in the U.S.: Who Has It, Who Doesn't, Aday and colleagues present a more complete discussion of this framework as well as presenting compelling data to inform what they then refer to as the "debate on the current 'state-of-the-nation' with respect to access." (60, p. 2) Accordingly, access is defined as

Those dimensions which describe the potential and actual entry of a given population group to the health care delivery system. The probability of an individual's entry into the health care system is influenced by the structure of the delivery system itself (the availability and organization of health care resources) and the nature of the wants, resources and needs that potential consumers may bring to the care-seeking process. The realization of the objective of entry is reflected in a population's reported rates of utilization

Consequently, the following variables emerge as critical for an examination of access issues: presence or absence of a regular source of care, distance one has to travel to care, insurance and coverage type, annual income, satisfaction, availability, various provider characteristics, site of care and convenience. Since the development of the Aday and Andersen conceptual framework many have studied access and expanded on the model, but the basic approach and model remain the same.

While health care access continues to be a major issue for health care in this country, one must keep in mind Patrick and Erickson's reminder that

Equity in access to health care, however, is a substantially different goal than equity in health-related quality of life. Equal access does not guarantee equal health outcomes because medical care cannot be assumed always to be effective. By affecting access to the benefits of health care, however, resource allocation also affects equity in health outcomes. (62, p. 16)

It is perhaps the incorporation of the concept of "equity" together with that of "access" that provides the most complete and accurate view of the barriers faced today in the American health care system. While many Americans from time to time experience barriers that result from the lack of health care equity and access, some patients experience these more often and to a greater degree than others. This is especially true for the racial and ethnic minorities. Particular attention must be given to the Hispanic population as the nation's largest racial/ethnic group, not only in the nation at large, but in many rural Midwestern communities where their growth has been unprecedented. (63) A recent study sponsored by the U.S. Department of Health and Human Services and published by the National Academy Press entitled Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (64) echoes the concerns raised by Patrick and Erickson (62). The report clearly and convincingly documents not only the racial and ethnic disparities in access, but also the lower quality health care received compared to that of whites, even when insurance status, income and severity of conditions are comparable. (64) Such issues are widespread and are found in all regions of the country including the rural Midwest. And, while white and blacks report the existence of such problems Andersen, Giachello and Aday found that "more than one-fifth of Hispanic families had one or more significant problems in obtaining needed [medical] services" (65, p. 238). These problems have been identified in a 2003 report that found several key barriers, including cost of services, frustration with the complexity of the health care system and language and cultural issues reported by Latinos in the rural Midwest. (63)

BARRIERS TO HEALTH CARE IN AMERICA

With an understanding of the concept of access and the historic factors that have influenced its investigation, one may first look to the report of the Medical Expenditure Panel Survey (MEPS) to identify some of the barriers faced in the modern health care system. Nearly 18 percent of the population surveyed reported not having a usual source

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of care; that is a “particular doctor’s office, clinic, health center or other place where they would usually go if they were sick or needed advice about health care.” (66, p. 1) The lack of a *usual source of care* is especially prevalent for Hispanics (30 percent), uninsured under age 65 (38 percent) and young adults ages 18 - 24 (34 percent). (66) A number of studies have identified a correlation between usual source of care and other variables that measure health care access and equity such as physician advice for prevention and type of insurance. (67)

The MEPS study indicates “among families that encountered problems in receiving care, those headed by Hispanics (69.1 percent) were more likely than those headed by persons in the white/other group (58.5 percent) to be unable to afford health care.” (66, p. 3) The study also indicates that the 20.9 percent of white/other group, 15.8 percent of the black group and 15.8 percent of the Hispanic group report insurance-related reasons as major barriers to health care. This is highly correlated with the fact that Hispanics and black are more likely than white Americans to be uninsured and lack private job-related health insurance. (66) Indeed, this is especially true of undocumented migrant workers who work in the rural Midwest. Iniguez and Palinkas report that nationally, almost 10 million Hispanics younger than 65 years are completely uninsured. In this 2003 study they write that “for Latino citizens and undocumented immigrants alike, health insurance status, and not ethnicity, language, or residency status, has been found to be the most important predictor of access to, and utilization of, health services.” (66, p. 2003) In a multivariate analysis Schur, Albers and Berk “conclude that financial factors—primarily insurance—remain as the paramount barriers to care” (69, p. 71) and go on to support this claim citing four studies from 1991 to 2000. The lack of health insurance is of particular concern for Mexican Americans who have the lowest level of insurance coverage among all Hispanic groups. (70) Little or no insurance coverage is a critical risk factor, as numerous studies indicate that the lack of health insurance is the major predictor of the lack of preventive services.

INFLUENCE ON BREAST CANCER SURVIVORSHIP

One of the greatest tragedies of the barriers to access and health care equity is that although Latinas have a lower incidence of breast cancer, they have a poorer survival rate than white women. This is due largely to the advanced stage of the disease at the time of diagnosis. Selvin and Brett report having a regular source of medical care as the most important predictor of cancer screening for all racial and ethnic groups, and having health insurance is associated with an increased likelihood of cancer screening. (71) They also report that cervical and breast cancer screening rates are lowest among Latinas. They further indicate that those women who may be motivated to receive screening are deterred in rural areas where travel times to health care providers may be extensive, Spanish is rarely spoken and Latinas have little if any social ties to their newly adopted towns.

SURVIVORSHIP

Breast cancer survivorship experiences among Latinas have been grossly understudied. One reason for this may be that there are problems inherent in the classification of ethnic backgrounds in large data sets. Another reason is that fewer Latina women survive

their cancers, an outcome resulting from limited screening and access to health care. Despite this, Aziz and Rowland argue there is a need to recognize and address the socio-economic and cultural variables that affect adaptation to and survival from cancer among diverse groups of survivors. (72) The few available studies that address the experiences of Latina breast cancer survivors (e.g., 73,74) suggest that Hispanic breast cancer survivors are most often distressed about disruptions to their daily lives, particularly with regard to social and familial relationships, changes in sexual relations and perceptions of desirability to male partners.

As Latina women become acculturated to mainstream U.S. life, their breast cancer screening behaviors will change and they will gain greater access to health care. Thus, researchers, health care professionals and social service worker need to begin preparing for the increased future needs. One way to prepare is to become more familiar with aspects of breast cancer such as incidence, disease presentation, lifestyle, health beliefs and access to health care as we have outlined above. Another method for preparing is to become familiar with culturally-relevant coping mechanisms so as to best facilitate positive coping experiences and quality of life among Hispanic breast cancer survivors.

Because research is scarce on coping during survivorship among Latinas, we must look at beliefs/values (e.g., *familismo* and spirituality) among Latino populations for guidance in understanding coping mechanisms. Within Latino cultures, the concept of *familismo* governs all things related to family interaction. *Familismo* refers to a collectivist orientation based on beliefs in strong family bonds and a sense of loyalty to family. (75,76) These more collectivist values commonly persist across U.S. Hispanic sub-groups despite sub-group differences and interactions with the more individualistic mainstream U.S. culture. (42,75) As an overarching value, this orientation has a significant impact on the experience of Latina breast cancer survivors, primarily in the role of social support from family members, friends, and other members of their social community in helping Latina women cope with breast cancer.

Dirksen and Erickson (2002) found that among Hispanic breast cancer survivors the influence of social support from family and friends was an important predictor of overall well-being during survivorship. (77) Similarly, Kellison (2002) found that Latinas tended to rely most heavily on spirituality and social support then other sources in coping with breast cancer. (78) Thus, Latina cancer survivors may place greater value on social support than non-Hispanic breast cancer survivors.

As discussed with regard to patient factors influencing survivorship, spiritual beliefs have an important influence on Hispanic health beliefs and behaviors. Because of the role that spirituality may play in the daily lives of Hispanic breast cancer survivors, we might conclude that such coping mechanisms as prayer, faith and the use of spiritual healers may also play a role in survivorship.

HEALTH INFORMATION USE DURING SURVIVORSHIP

Kellison (2002) found that among the Latinas she interviewed, 80 percent described the feeling that they had not been given enough information about their diagnosis, treatment, prognosis and the lasting impact of their breast cancer. (78) While lack of appropriate and timely breast cancer related information is something many women face (79),

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providing this information to Hispanic women appears to be particularly challenging. (80,81) The largest obstacle to overcome with this information is not just language or educational levels; it is addressing the influential underlying cultural beliefs that impact health behaviors. (82) Morgan and colleagues (1995) argue that it is essential to offer breast cancer related information that coincides with prevailing cultural beliefs and expectations in order for the information to be effective. (83) At the same time, Hudson and Watts (1996) suggest that it is not only the packaging of information within cultural beliefs and expectations that is necessary, it is also important to consider the format of the information. (84) The researchers found that Hispanics rely less frequent on newspapers than television or radio and very infrequently use magazines as sources of health information. Also, Hispanics reported primarily getting information in general from television and radio with preferences for information from culturally specific media (e.g., Univision, Telemundo, etc) (84) Similarly, Valdez found that Latinas preferred information about breast cancer in formats that depicted individuals similar in appearance and behaviors to themselves. (85) When it comes to health information, Hudson and Watts found that Hispanics were more likely to rely on information received from family members and friends than that received from health care professionals. (84)

RECOMMENDATIONS FOR FUTURE RESEARCH

While health care in America has improved in the last century for many subgroups of the population through public and private initiatives, the combined concepts of access and equity in health care remain one of the most difficult challenges facing health policy and the American health care system. Many approaches have been attempted to address this disparity with varying levels of success. And while some Americans have achieved progress in overcoming the barriers to access and increased equity, for Latinas with breast cancer and those concerned about their care these issues have become exacerbated as large numbers of Hispanics immigrate from Mexico and Latin America and migrate from the cities of the North and Northeast to the Midwest.

The following are recommendations for areas of future research: a) a general expansion in the focus of research on Latinas and breast cancer, which has long revolved around prevention and screening issues, to include survivor experiences; b) expansion of research foci beyond the experiences of Latinas in urban and metropolitan areas to include Latinas from rural areas, such as those in the Midwest; c) development and implantation of rigorous research designs that focus on biological risk factors for breast cancer among Latinas to improve odds of achieving long-term survivorship; and d) investigation of Latinas use of complementary/alternative therapies as they relate to cultural-mediated health beliefs and survivorship experiences.

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ABOUT THE AUTHORS

M. Elise Radina, Ph.D., CFLE, is an assistant professor of family services in the department of Design, Family and Consumer Sciences at the University of Northern Iowa.

Daniel R. Longo, Sc.D., is a professor of family and community medicine at the University of Missouri-Columbia.

Jane M. Armer, Ph.D., R.N., is an associate professor in the Sinclair School of Nursing, and director of nursing research, Ellis Fischel Cancer Center at the University of Missouri-Columbia.

CORRESPONDING AUTHOR

M. Elise Radina, Ph.D., CFLE
229 Latham Hall
Design, Family and Consumer Sciences
University of Northern Iowa
Cedar Falls, IA 50614
(319) 273-2401 (o)
(319) 273-7096 (f)
Elise.Radina@uni.edu