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The Role of Legislation and Practitioner Perceptions on the Availability of Patient Navigation Programs

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The Role of Legislation and Practitioner Perceptions on the Availability of Patient Navigation Programs

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by

Annalyn Balugay Valdez Dadia

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ABSTRACT OF THE DISSERTATION

The Role of Legislation and Practitioner Perceptions on the Availability of Patient Navigation Programs

by

Annalyn Balugay Valdez Dadia
Doctor of Public Health in Health Services
University of California, Los Angeles, 2014
Professor Ninez A. Ponce, Co-Chair
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Background: Immigrants with limited English capabilities and limited knowledge about the U.S. health care system may experience challenges in accessing and utilizing cancer care services. Patient navigation programs (PNPs) are emerging as a viable strategy to improve health care at the financial, organizational, social and cultural level. The Patient Navigator Outreach and Chronic Disease Prevention Act (NOA) has the potential to increase the availability of PNPs and to improve timeliness to treatment. Practitioner perceptions of PNPs are missing from the literature, and could provide evidence needed to generate support for the integration and adoption of PNPs at the system level. This dissertation is comprised of two studies that investigate the availability and quality of PNPs in Los Angeles (LA) and Orange County (OC) facilities, and the perceptions of practitioners and navigators serving Southeast Asians.

Methods: Study 1 involved facility-level data collected through two surveys (Short Telephone Questionnaire and Facility Survey) and tumor registry data from the Los Angeles Cancer Surveillance Program. Study 2 used secondary data of transcripts of interviews with practitioners (n=14) and patient navigators (n=9).

Results: Study 1- Survey responses revealed that legislation was not associated with the development and availability of PNPs in LA or OC facilities, but compliance with hospital certification requirements did. The proportion of patients who received surgery within 30 days was higher at pre-NOA period at facilities with PNPs. Unexpectedly, post-NOA median time to surgery after diagnosis increased regardless of the availability of PNPs,

Study 2 - Practitioner perceptions of PNPs highlighted the benefit of PNPs and the need to inform cancer care clinicians and institutions about the value of navigation services to improve patient-physician communication. Navigators were instrumental in helping patients understand the disease and treatment process better, and enabled patients to be more engaged in dialogue with their physicians.

Conclusion: PNPs have evolved into a mechanism for assisting under-resourced communities. Legislation alone needs to be bolstered with institutional program commitment and requirements. Practitioner perceptions of PNPs expressed in this study confirm the need to inform cancer care clinicians and cancer care institutions about the value of patient navigation services.

The dissertation of Annalyn Balugay Valdez Dadia is approved.

Roshan Bastani

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University of California, Los Angeles

2014

For my mother,
Zenaida Balugay Valdez.
Thank you for instilling in me a passion for learning,
encouraging me to always follow my dreams, and
supporting my decisions. Your sacrifices are the reason for
my accomplishments.

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CHAPTER 1

Introduction to Dissertation

Patient navigation programs (PNPs) are emerging as a viable strategy to reduce health care disparities and improve health care access at the financial, organizational, social and cultural level. Enactment of the Patient Navigator Outreach and Chronic Disease Prevention Act (NOA) of 2005 serves as legislative recognition for the need to assist communities with the greatest health care needs, such as lack of health insurance, limited knowledge of the U.S. health care system, or the inability to communicate with health care providers. This dissertation is comprised of two studies that investigate patient navigation programs and breast cancer care. Specifically, the research focuses on Los Angeles and Orange County facilities and practitioners serving Southeast Asians, and aims to address the following three questions about the influence of the NOA: 1) did the federal act lead to improved availability of patient navigation programs for Southeast Asian women with breast cancer, 2) did the federal policy improve time to treatment and quality of care for Southeast Asian women with breast cancer, and 3) did perceptions from breast cancer health care practitioners convey positive testimony for research advocacy networks to influence the adoption and integration of PNPs into health services for under-resourced populations.

This chapter provides the background on PNPs and breast cancer incidence among Southeast Asians, and an overview of the client organization, the Asian American Network for Cancer Awareness, Research, and Training (AANCART), for this Doctorate in Public Health (DrPH) dissertation. This chapter then concludes with a description of each study. Chapter 2 presents the conceptual framework used to guide this dissertation. Chapter 3 elaborates on the study that examines the effect of the policy on the availability of patient navigation services and its impact on the quality of breast cancer care received. Chapter 4 presents the study associated with health care practitioners' and patient navigators' perceptions of PNPs. The final chapter summarizes the dissertation findings and the recommendations for the client organization.

1.1 – Definition of Patient Navigation

Social workers, nurse navigators, case managers, care coordinators, community health workers, and lay health aides are just a few of the job titles used to refer to individuals who assist patients through the health care process. According to the current literature, these roles have more commonly been referenced as patient navigators (Institute for Alternative Futures, 2007; Varner, 2010; Wells et al., 2011). Numerous attempts have been made to define patient navigation, but due to the diversity of ways in which PNPs have been implemented, a succinct and single definition is problematic. Although no standard definition for patient navigation has been agreed upon, initial attempts were conducted by the U.S. Center for Medicaid and Medicare Services (CMS) and the Canadian Breast Cancer Initiative (CBCI) to define patient navigation in terms of services provided: 1) connecting individuals to screening, 2) following patients post-screening, and 3) assisting patients through course of treatment (Braun et al., 2012; Dohan & Schrag, 2005). As an initial attempt, the definition by CMS and CBCI limited navigators to screening services, which is one aspect in an array of tasks and assistance that patient navigators can offer.

"C-Change: Collaborating to Conquer Cancer" is a national organization composed of key leaders from the public, private, and not-for-profit sectors of the cancer community with a mission to eliminate the cancer burden by collectively identifying resources and opportunities for action to end cancer. Unlike CMS and CBCI, C-Change attempted to define patient navigation in more holistic terms rather than services within the cancer continuum (C-Change, 2012). The growing interest in reducing cancer disparities prompted the Oncology Nursing Society, the

Association of Oncology Social Work, and the National Association of Social Workers to come together in an attempt to provide a more refined definition by adapting the C-Change description of patient navigation as **“individualized assistance offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from prediagnosis through all phases of the cancer experience”** (C-Change, 2012; ONS, 2009; PN Promotion Initiative Workgroup, 2005). Additionally, the National Cancer Institute’s (NCI) patient-centric definition of a patient navigator is **“someone who understands the patient’s fears and hopes, and who removes barriers to effective care by coordinating services, increasing the cancer patient’s chances for survival and quality of life”** (McDonald KM, 2007). This NCI definition is further supported by the investigative research of Vargas and colleagues, which examined the original PNPs and described patient navigation as a system that charges an individual, familiar with the system of care, to move the patient through the entire health care system (Vargas, Ryan, Jackson, Rodriguez, & Freeman, 2008).

1.1.1 Background of Patient Navigation

Early studies on the use of patient navigators among English proficient Caucasian and African American women were found to improve access to care, such as increase in screening, timely diagnosis of breast abnormalities, and adherence to follow-up diagnostic procedures and treatment (Battaglia, Roloff, Posner, & Freund, 2007; Fouad, Wynn, Martin, & Partridge, 2010; Freeman, 2006; Giese-Davis et al., 2006; Psooy, Schreuer, Borgaonkar, & Caines, 2004). Research indicates that patient navigators facilitate access to care and assist cancer patients on multiple levels, ranging from 1) addressing instrumental needs, such as providing information, reducing financial stressors and stewarding the application for and optimal use of health insurance; 2) providing functional support, such as assistance with appointments and transportation; and to 3) offering emotional support when needed, such as helping patients cope with feelings of depression and isolation (Carroll et al., 2010; Carroll, Winters, Purnell, Devine, & Fiscella, 2011; Davis, Darby, Likes, & Bell, 2009; Natale-Pereira, Enard, Nevarez, & Jones, 2011). Patient navigation has also been identified as a tool to deliver better quality and efficient care through timely diagnosis, initiation of treatment, and adherence to treatment modalities (Battaglia et al., 2007; Ell, Vourlekis, Lee, & Xie, 2007; Ell et al., 2009; Ferrante, Chen, & Kim, 2008; Freund et al., 2008; Koh, Nelson, & Cook, 2011; Psooy et al., 2004).

To evaluate the benefit of patient navigation, Ell et al. attempted to conduct a randomized clinical trial through a pre-post study design using volunteers to test the effectiveness of patient navigation after an abnormal mammogram among non-English speaking Latinas. Their findings indicate that use of a PNP, coupled with structured counseling, resulted in improved follow-up adherence rates and timely diagnostic resolution compared to usual care and non-participation in the study (Ell et al., 2007). A randomized control trial (RCT) design by Ferrante and colleagues examined the effectiveness of a patient navigator in improving the quality of care after an abnormal mammogram. Among African-American and Hispanic patients the study showed that the use of navigation services decreased anxiety levels, increased patient satisfaction, and decreased time to diagnostic resolution (Ferrante et al., 2008). Only a handful of studies (six total found) has investigated the utility of PNPs among Asian Americans (AAs), two of which focused on breast and cervical cancer screening behaviors (Korean American women in Los Angeles, CA and Chinese American women in New York, NY) (Maxwell, Jo, Crespi, Sudan, & Bastani, 2010; Wang, Fang, Tan, Liu, & Ma, 2010), a third focused on the awareness of colorectal cancer risk factors (Korean American church members, location undisclosed) (Ma, Shive, et al., 2009), and a few specifically looked at the roles and perspectives of navigators serving AAs (multi-ethnic groups, nationwide; Cambodian and Laotian communities in Southern California; Cambodian, Laotian, Thai and Vietnamese women in Southern California) (Braun et al., 2012; T. Nguyen, Tanjasiri, Kagawa-Singer, Tran, & Foo, 2008; T. N. Nguyen, Tran, Kagawa-Singer, & Foo, 2011).

Despite the fact that the majority of studies allude to a multitude of benefits, navigators are not readily available to newly diagnosed cancer patients and PNPs have not been institutionalized. Factors contributing to the low adoption of PNPs include the absence of data in the literature supporting the influence of PNPs on cancer-related morbidity and survival, the dearth of research on the economic effect of patient navigation services in relation to sustainability, and the need for data on organizational impacts of PNPs (i.e. decline in "no shows", more effective use of clinical/administrative staff time, and feasibility of replicating the program) (Paskett, Harrop, & Wells, 2011; Ramsey et al., 2009; Whitley et al., 2011). Other reasons for the lack of serious consideration of PNPs may be attributed to methodological issues associated with small sample sizes, shortage of studies that used controlled trials to evaluate the effectiveness of PNPs in improving health outcomes, lack of rigorous research that investigated the efficacy and cost-effectiveness of patient navigators in improving cancer care, and the overall absence of health care system funding to provide patient navigation services (Ferrante et al., 2008; Hopkins & Mumber, 2009; Lee et al., 2011; Parker et al., 2010; Paskett et al., 2011; Wells et al., 2008; Whitley et al., 2011).

1.1.2 Importance of Patient Navigation Programs

A systematic review of published research on NCI-funded PNPs was conducted by Robinson-White (2010) to investigate the efficacy and cost-effectiveness of PNPs on patient outcomes (i.e. screening, diagnosis, treatment, and clinical trial participation). Pubmed and Ovid databases were used to identify scientific literature between January 1990 to April 2009, resulting in a total of 12 data-based articles that investigated patient navigator efficacy in breast cancer (Robinson-White, Conroy, Slavish, & Rosenzweig, 2010). Findings indicate that PNPs improved adherence to breast cancer care, but were more commonly applied to assisting patients with access to screening and early diagnosis than adherence to treatment (Robinson-White et al., 2010).

Wells, et al. conducted a review of the literature on cancer patient navigation and found some evidence of efficacy for patient navigation to increase participation in cancer screening and diagnostic follow-up after abnormal screening, but less evidence in the efficacy of patient navigation to reduce late-stage cancer diagnosis or delays in the initiation of cancer treatment (i.e. primarily low-income, non-English speaking Latinas) (Wells et al., 2008). A follow-up to this literature review was conducted by Paskett, Harrop and Wells, which involved articles published between November 2007 through July 2010 (Paskett et al., 2011). Findings suggest evidence is building to demonstrate that PNPs have contributed to the increase in cancer screening rates, but the literature still lacks substantive proof to support patient navigation in the areas of diagnostic follow-up, treatment adherence and cancer survivorship (Paskett et al., 2011). Although a systematic literature review of studies published after July 2010 has not yet been conducted, a brief overview of the current research indicates that use of PNPs among ethnic communities continue to positively assist patients in obtaining diagnostic follow-up care, and investigations associated with proactive approaches to care, such as the combined use of patient navigators and “communication coaching” of patients/family members, have contributed to improvements in cancer treatment (primary outcomes included timeliness of care, patient satisfaction, and quality of life) (Carroll et al., 2010; Guadagnolo, Dohan, & Raich, 2011;

Hendren et al., 2010). Nevertheless, there is still a paucity of research on AA women's use of patient navigation in access and utilization of health care services.

1.1.3 Importance of Patient Navigation for Asian Americans

Immigrants, especially those with limited English language capabilities and limited knowledge about the U.S. health care system, have difficulty navigating the U.S. health care network, and often will not know how to identify the resources and services to obtain and access appropriate cancer care. According to the U.S. Department of Health and Human Services, individuals with limited English proficiency (LEP) are defined as "persons who are unable to communicate effectively in English because their primary language is not English and they have not developed fluency in the English language", such that these individuals have difficulty speaking or reading English. A September 2013 report by the Asian and Pacific Islander American Health Forum (APIAHF) reveals that among AAs in California, 17.74% of U.S.-born Asians and 55.74% of foreign-born indicate speaking English "not well" or "not at all" (Asian and Pacific Islander American Health Forum, 2013). Additionally, an estimated 23.1% in Los Angeles county and 10.1% in Orange county indicated speaking English less than "very well" (U.S. Census Bureau, 2012a) and nationally, over 36% of AAs are deemed to be linguistically isolated (Ye, Mack, Fry-Johnson, & Parker, 2011). Within the Los Angeles-Long Beach-Santa Ana, California metropolitan area, 21.3% of individuals 5 years and older spoke an Asian/Pacific Islander language, other than English, at home (Ryan, 2013).

Patient navigation serves as an important service for AAs since additional time and effort may be needed to navigate care for them, which may not only be attributed to language capacity but lack of education and knowledge about the existing health care system as well (Han, Lee, Kim, & Kim, 2009; Wells et al., 2011). Additionally, being a female from any ethnic community (particularly, Hispanic women) resulted in more barriers and increased need for navigation services, such that non-English speaking, low-income minority women are more likely to delay or miss diagnostic and treatment follow-up exams, which is often associated with the breakdown in patient-provider communication (Carroll et al., 2011; Ell et al., 2007).

A few studies have been conducted to demonstrate the effectiveness of patient navigation in improving timeliness to care at different stages of the cancer continuum, among different ethnic groups (Ferrante et al., 2008; Gabram et al., 2008; Guadagnolo, Boylan, et al., 2011; Petereit DG, 2008; Wells et al., 2011). One of the few studies to implement a randomized control intervention to investigate adherence to diagnostic follow-up exams among a low-income, AA ethnic community found peer navigation to be successful in increasing knowledge and self-efficacy to complete diagnostic exams. (Maxwell et al., 2010). Research that attempted to measure the impact of PNPs suggested that culturally tailored types of programs were too expensive and additional research was required to assess its cost-effectiveness (Ferrante et al., 2008; Freund et al., 2008; Schwaderer & Itano, 2007). Other studies also indicated that PNPs were difficult to replicate due to the absence of consistent parameters, such that many programs were tailored to meet the needs of the target community, which further contributes to the inability to establish best practices and assess outcome measures (Campbell, Craig, Eggert, & Bailey-Dorton, 2010; Robinson-White et al., 2010; Varner, 2010). Although research on the effectiveness of patient navigation among AAs is limited, investigations of PNPs point out the need for targeted systemic interventions at the organizational level to identify populations at risk and ethnic communities with the greatest cancer care disparities (Carroll et al., 2011; Shockney, 2010; Zapka, Taplin, Price, Cranos, & Yabroff, 2010).

1.1.4 Patient Navigator Outreach and Chronic Disease Prevention Act

Led by Dr. Harold Freeman, the 2001 President’s Cancer Panel Report on the current state of the health care system “Voices of a Broken System”, with a focus on cancer care, highlighted the fact that although cancer research has been very productive, health disparities in access and utilization continues to exist, and the disconnect lies in the current system (Freeman, 2001). The existing U.S. health care system provides services from the point of diagnosis forward, yet the intricate network to access these services makes it difficult to get from one end of the system to the other, especially when an individual is unfamiliar with such a complex matrix and communication is not clear or consistent between practitioners or health care service departments.

In 2005, the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 - Public Law 109-18 (NOA) was signed as an amendment to the Public Health Service Act of 1944 (U.S. Government Printing Office, 2005). The NOA granted the Secretary of Health and Human Services the authority to award $25 million, over five years, to "make grants eligible to entities for the development and operation of demonstration programs to provide navigator services to improve health care outcomes" (U.S. Government Printing Office, 2005). The primary purpose of the act was "to determine if patient navigators help reduce barriers to access to care and improve health care outcomes in underserved patient populations" (U.S. Government Printing Office, 2005; Urrea, 2009).

According to the Health Resources and Services Administration (HRSA) Fiscal Year 2012 report, funds from the NOA were not appropriated until 2008, and the allocation was less than $3 million, followed by appropriations of $4 million in 2009, approximately $5 million in 2010 and another $5 million was budgeted for 2011 (Dept. of Health and Human Services, 2012). The six grantees from Fiscal Year (FY) 2008 conducted two-year projects, which resulted in 37 trained navigators and 6,500 navigated patients, while FY 2009 included two grantees that were funded for one-year projects, FY 2010 generated 10 grantees with three-year projects, and

FY 2011 budgeted for 10 grantees with an average award of $400,000 (Dept. of Health and Human Services, 2011, 2012). Of the 10 awards in FY 2010, four of the grantees were from California and are located in the city of Bakersfield, Vista, San Diego, and Palo Alto (Health Resources and Services Administration, 2012). By the end of FY 2011 a total of 1,359 patients with chronic illnesses were navigated by FY 2011 grantees, and no additional awards were generated for FY 2012 or FY 2013 (Dept. of Health and Human Services, 2013). The NOA was authorized as a demonstration program and information about the sustainability of the PNPs generated by the grantees is not available, however, a Report to Congress will be submitted at the conclusion of the program (Dept. of Health and Human Services, 2013). Within the parameters of the Patient Protection and Affordable Care Act (ACA), the NOA was reauthorized through 2015, allowing institutions to apply for grants for the development and establishment of PNPs (George Washington Cancer Institute, 2013).

1.1.5 Asian American Breast Cancer Incidence

Breast cancer is the leading cause of death for AA women, compared to heart disease for non-Hispanic White women (Centers for Disease Prevention and Control, 2013). In contrast to their higher mortality rates, the age-adjusted breast cancer incidence rate for Asians and Pacific Islanders (93.7 per 100,000 women) was lower than that for non-Hispanic white women (127.3 per 100,000) among those diagnosed between 2004-2008 (Howlader N, 2011). Thus there appear to be disparities in breast cancer survival between AA's and NHW's despite the lower incidence among AA's.

Breast cancer data comparing Asians to other racial groups suggest that Asians have better health outcomes for some measures. The use of aggregated data, including all of the subgroups that make up APIs in one category, is a major factor perpetuating the myth that AA's are healthy and are untouched by the cancer burden (M. S. Chen, Jr. & Hawks, 1995). Cancer disparities exist for AA subgroups at every level of the cancer continuum, from low screening rates, differences in treatment patterns, limited access to health care, to more aggressive tumor characteristics. Disaggregated data presents a better picture of the issues AA subgroups encounter when trying to access timely cancer care (Bigby & Holmes, 2005; J. Y. Chen, Diamant, Kagawa-Singer, Pourat, & Wold, 2004; Gomez et al., 2013; Kagawa-Singer & Pourat, 2000; Kagawa-Singer et al., 2007; Smigal et al., 2006; Srinivasan & Guillermo, 2000).

Additionally, among the larger subgroups of Asian immigrant women (e.g. Chinese, Japanese, Filipinos, Koreans and Vietnamese), living in the U.S. for at least one decade is associated with an increased risk (80%) of developing breast cancer compared to recent immigrants (Deapen, Liu, Perkins, Bernstein, & Ross, 2002; Kwong, Chen, Snipes, Bal, & Wright, 2005; Ziegler et al., 1993). The challenges experienced by immigrant AAs contribute to the overall increase in cancer health disparities among this population. For instance, immigration status and country of birth has been found to negatively affect health care access and screening behaviors among AAs (Pourat, Kagawa-Singer, Breen, & Sripipatana, 2010; Ye et al., 2011).

In 2004, the Centers for Disease Control and Prevention (CDC) published findings from a study comparing 1) survey results administered to one Cambodian and three Vietnamese communities from the Racial and Ethnic Approaches to Community Health (REACH) 2010 project conducted during 2001-2002 and 2) a survey conducted with Asians (in aggregate) and the general U.S. population from the 2002 Behavioral Risk Factor Surveillance System (BRFSS). The health status results from this analysis indicated that Cambodians and Vietnamese had substantially different health-risk profiles than both the aggregate Asian population and the general U.S. population (Koch-Weser, 2004). More specifically, Cambodians and Vietnamese were found to be at least three times as likely to report not visiting a doctor because of cost compared to all Asians and U.S. residents, and Cambodian and Vietnamese women had lower rates of Pap tests (64.2% and 65.5%, respectively) than women in the aggregate Asian and general U.S. populations (74.5% and 85.8%, respectively) (Centers for Disease Prevention and Control, 2004; Koch-Weser, 2004).

A recent report from the Los Angeles Cancer Surveillance Program emphasizes the fact that breast cancer remains the most common cancer among women, especially those residing in the Los Angeles (LA) county region (Cockburn, Liu, Deapen, & (eds), 2009). Among Southeast Asians (SEAs), the breast cancer distribution (compared to all cancer sites combined) for Vietnamese women was 25.3% and slightly higher for the aggregated Thai, Hmong, Cambodia, and Laotian (THCL) women at 31.1% (Cockburn et al., 2009). Although trends in the age-adjusted incidence rates among female breast cancer in the LA area shows a decline among non-Hispanic whites (NHWs) (approximately 165 per 100,000 between 1996-2000 to approximately 150 per 100,000 between 2001-2006), the same cannot be said for most Asian subgroups, such that incidence rates continue to increase among THCL (approximately 70 per 100,000 between 1996-2000 to approximately 93 per 100,000 between 2001-2006) and decline among Vietnamese (approximately 95 per 100,000 between 1996-2000 to approximately 80 per 100,000 between 2001-2006) (Cockburn et al., 2009). More specifically, the changes in age-adjusted incidence rate between 2001-2006 shows an increase for THCL women that is more than half the rate of NHWs and almost half the rate for Vietnamese women. A recent study on the age-adjusted incidence rates (1990-2008) among AA populations nationwide further supports the fact that breast cancer has grown to become the top cancer site for Cambodian (ranked 3rd with a rate of 19.6 in 1990-1994 to ranked 1st with a rate of 43.4 in 2004-2008), Laotian (ranked 4th with a rate of 22.5 in 1990-1994 to rank 1st with a rate of 41.3 in 2004-2008) and Vietnamese (ranked 1st between 1990-2008 with a rate of 52.3 in 1990-1994 to a rate of 63.0 in 2004-2008) women (Gomez et al., 2013).

1.1.6 Demographic Information on Southeast Asians

The 2012 report from the Pew Research Center indicates that for the first time in history, Asian immigrants (approximately 36% or 430,000) surpassed the number of Hispanic immigrants (approximately 31% or 370,000) arriving in the U.S. in 2010 (Pew Research Center, 2012). According to data from the 2010 Census Bureau, the population of Asians (alone or in combination) increased more than four times faster (46% versus 43% for Hispanics) than any other group between 2000 (11.9 million) and 2010 (17.3 million), which equates to 5.6% of the U.S. population for a total of 17.3 million out of 308.7 million (Hoeffel EM, 2012). More specifically, the population of Asians increased by 46% (11.9 million in 2000 to 17.3 million I 2010) compared to 43% for Hispanics (35.3 million in 2000 to 50.5 million in 2010) (Ennis SR, 2011; Hoeffel EM, 2012). Of the 23 Asian subgroups identified by the U.S. census, six were listed as the major Asian population groups in the nation and include: Asian Indian (19.9%), Chinese (24.1%), Filipino (18.1%), Japanese (5.7%), Korean (10.0%) and Vietnamese (11.1%) (Hoeffel EM, 2012). Although the Pew report highlights the successes of AA in areas such as education, group relations and attitudes, the information provided is not representative of the challenges (e.g. 42.3% of NHWs and 57.0% of AAs need language assistance) and health disparities (e.g. 67.3% of NHWs and 54.0% of AAs received a mammogram within the past 2 years) often encountered by smaller AA subgroups (Natale-Pereira et al., 2011). The report does, however, allude to the fact that the increasing Asian immigrant population, and the heterogeneity of subgroups, warrants the need for substantial health care services and resources to address their potential health care issues. Reviews of the literature show that Asian immigrants report poorer health care access (Ye et al., 2011).

Southeast Asia can be defined as the area south of China and east of India, and include population groups from the countries of Burma, Thailand, Laos, Cambodia, Vietnam, Malaysia, Brunei, Indonesia, Singapore and the Philippines (Chandler et al., 1987). Statistics from the 2010 U.S. Census Data show Filipinos and Vietnamese to be the two largest immigrant groups from Southeast Asia, followed by Hmong, Cambodians, Laotians, Thais, Burmese, Indonesians, and Malaysians in descending order (see Table 1.1) (Hoeffel EM, 2012).

Table 1.1 - Population of Southeast Asian Subgroups in the U.S.

Southeast Asian (SEA) Subgroups	Number in U.S.	Rank by population size
Filipinos	2,555,923	1
Vietnamese	1,548,449	2
Hmong	247,595	3
Cambodians	231,616	4
Laotians	191,200	5
Thais	166,620	6
Burmese	91,085	7
Indonesians	63,383	8
Malaysians	16,138	9
Singaporean	3,418	10

Source: U.S. Census Bureau, 2010 Census special tabulation.

Although Filipinos and Hmong rank among the top three SEA groups in the U.S. by population size, they are not included in this dissertation study. The long-standing immigration history and political relationships between the U.S. and the Philippines since the turn of the 20th century and the higher education and income levels of Filipino immigrants has provided this community with greater knowledge and awareness of the resources in their new country of residence compared to other SEA immigrant groups (Cordova, 1983; Frisbie, Cho, & Hummer, 2001). The number of Hmong living in Los Angeles (LA) and Orange County (OC) is less than 3,000 in contrast to the 6,000+ for the other SEA communities identified for this study (U.S. Census Bureau, 2012d). Therefore, the sample size of breast cancer patients for this group is likely to be too small for meaningful analysis.

A close examination of the 4 target SEA subgroups (Cambodians, Laotians, Thais, and Vietnamese) reveals that there were 231,616 Cambodians, over 191,200 Laotians, 166,620 Thais and 1,548,449 Vietnamese living in the United States in 2010 (Hoeffel EM, 2012). Of these four SEA groups, over a third of each community group resides within California alone and nearly half are located in the LA and OC regions (see Table 1.2).

Table 1.2 - Population of Southeast Asian (SEA) Subgroups by Location

Southeast Asian (SEA) Subgroup	Number in U.S.	Number in California (CA)	Percent of U.S. subgroup population in CA	Number in Los Angeles County (LA)	Number in Orange County (OC)	Total Number in LA & OC	Percent of CA Subgroup population in LA & OC
Cambodian	231,616	88,141	38%	32,201	6,181	38,382	44%
Laotian	191,200	63,678	33%	3,555	2,991	6,546	10%
Thai	166,620	50,926	31%	23,803	4,026	27,829	55%
Vietnamese	1,548,449	567,833	37%	90,431	170,256	260,687	46%

Source: U.S. Census Bureau, 2006-2010 American Community Survey, (2010 Census, SF4, Table B01003)

1.1.7 Health Care Utilization by SEA Subgroups

Health related data for these SEA groups are limited, and breast cancer statistics on Cambodian, Laotian, Thai and Vietnamese women are scarce and difficult to find. The lack of published studies on these communities may often be attributed to small population sizes. Information for SEA women is frequently inferred from aggregated Asian American and Pacific Islander data, but such data is often insufficient in depicting the unique health care access limitations encountered by this sub-population.

1.1.7.a - Cambodian

In 2006 the Asian Pacific Islander American Health Forum (APIAHF) published a series of health briefs that summarized the health and health care access issues among a number of AA populations (Asian and Pacific Islander American Health Forum, 2006). APIAHF's research on the Cambodian community in the U.S. showcased the demographic effects that Pol Pot's rule and the Khmer Rouge regime had on this immigrant group, such that Cambodians were found to have the lowest socio-economic indicators among AAs (approximately 54% live below the 200%

poverty line), have lower educational attainment levels (9% hold a bachelor's degree and 53% have less than a high school education), and were less likely to have or afford health insurance (27% uninsured, 20% Medicaid, 49% employer-based, and 4% private) as a result of citizenship status (15% of Cambodian citizens and 42%-51% of Cambodian non-citizens do not have health coverage) (Asian and Pacific Islander American Health Forum, 2006). With regards to health, APIAHF's research indicated that Cambodians in California were four times more likely to have a stroke than the general white population, and a study on Cambodian refugees in Long Beach, California were found to have elevated rates of post-traumatic stress disorder (62%) and depression (51%) (Asian and Pacific Islander American Health Forum, 2006).

Looking at differences in utilization and access to cancer care services, earlier studies on Cambodian communities found that cancer screening rates were below the national average, such that only a third (36%) of women age 40 and older had ever received a mammogram and less than a quarter (24%) had ever received a Papanicolaou (Pap) test (Taylor et al., 1999; Tu et al., 2000). The more recent research on cervical mortality rates among Cambodians indicate that Cambodian women have a 95% higher risk of dying from cervical cancer when compared to non-Hispanic white (NHW) women, which may be attributed to insufficient Pap tests (Kem & Chu, 2007). On a slightly more positive note, in a study that compared Cambodians to Somali and Vietnamese immigrants, cancer screening rates among Cambodians were found to be higher, which may be associated with their duration of residence in the United States (Samuel, Pringle, James, Fielding, & Fairfield, 2009). A health assessment of the Cambodian community in Seattle, Washington found that Cambodians were unfamiliar with the Western concepts of cancer and held different perceptions of health and disease, which may present dilemmas for health educators when trying to convey health related information, such as preventive screenings

(Seng et al., 2005). A multi-ethnic study on language proficiency and health care comprehension found Cambodians to have the highest rate (10.6%) of limited English proficiency (LEP) in comparison to other AA groups, and they were the most likely (95%) to report problems understanding medical situations (Wilson, Chen, Grumbach, Wang, & Fernandez, 2005). These findings may also suggest the disparities that exist in the data, especially when exploring the health of Cambodians.

1.1.7.b - Laotian

An investigation on the health statistics of Laotians showcases the paucity of data on this population. Available information on Laotians is often combined with other immigrant or refugee communities and only provides a glimpse of the inequalities affecting this vulnerable group. A study by Chen in 2005 found that among SEAs, Laotians were one of three communities with the lowest rates of adults, age 25 or older, to hold a bachelor's degree (6.3%) when compared to the U.S. mean (15.6%) and they were one of nine AA groups to have the lowest numbers of individuals with any formal schooling compared to the U.S. population (1.4%) (M. S. Chen, Jr., 2005b).

The earliest attempt at determining the level of cancer knowledge and screening among Laotians was conducted by Bailey and colleagues in 1996. The study by Bailey found that Laotian and Cambodian women had the lowest levels of breast cancer screening knowledge compared to Hispanics, and that uncommon mechanisms of cancer education and services (i.e. individualized breast self exam lessons and home follow-up on breast self exam teachings) were more effective at overcoming screening barriers than usual means (i.e. physician referral and print media) (Bailey, Bennett, Hicks, Kemp, & Warren, 1996). A more recent investigation on the cancer incidence (rates calculated as the average annual per 100,000 age-adjusted to the 2000 U.S. standard population) and mortality rates among specific AA populations in the U.S. indicate that breast cancer incidence rates (36.9%) among Laotian women ranked second behind lung cancer (44.4%), but little else is known about mortality rates for this population due to small sample sizes (Miller, Chu, Hankey, & Ries, 2008). Thus far, the research conducted by Yang and Mills is the only one that focused specifically on the Laotian community, which found that Laotian men and women (residing in California) had statistically significant elevated risks for non-Western types of cancers, such as nasopharyngeal, stomach, and liver cancers (Yang & Mills, 2009).

1.1.7.c - Thai

Similar to Laotians, information on the health statistics of Thai women in the U.S. is limited. Many of the publications focused on Thais were conducted in Thailand and little is known about the Thai community in the United States. The background information that is available about this population show rates of educational attainment for Thais, age 25 years and older, were lower (18.8% have a high school diploma) than the U.S. general population (29.0%) and the proportion of Thais with no health insurance coverage was higher (22.8%) than the U.S. national average (15.5%) (U.S. Census Bureau, 2012b, 2012c).

The majority of cancer data on Thai women indicate that cervical cancer was the most common cancer among women in Thailand, followed by breast cancer (Aphinives, Punchai, Vajirodom, & Bhudhisawasdi, 2010; Jordan et al., 2009; Kritpetcharat et al., 2003; Thongsuksai, Chongsuvivatwong, & Sriplung, 2000; Wiwanitkit, 2006). In the U.S., research on cervical cancer screening rates among Thai women in Northern California found 74% of Thai women had received a Pap test and 61% were screened within the last three years, which may have been attributed to physician referrals (Tsui & Tanjasiri, 2008). Although these rates may be significant for this immigrant community, the rates were still below the national average of 92% for Pap tests and 82% for cervical cancer screenings within the last three years (Tsui & Tanjasiri, 2008).

1.1.7.d - Vietnamese

According to the research conducted by APIAHF in 2006, the Vietnamese community had the highest LEP rate (61%) than any other AA group, which suggests that this group requires more assistance when accessing health care services due to the fact that language proficiency has been known to greatly impact health access (Asian and Pacific Islander American Health Forum (APIAHF), 2006). Although the median household income for Vietnamese was greater than the national average (approximately $44,800 versus $41,900), Vietnamese households are larger than the general population (3.7 persons versus 2.6 persons, respectively) and families tend to reside in areas with higher costs of living, which the APIAHF report indicated may contribute to higher levels of poverty and disease (Asian and Pacific Islander American Health Forum (APIAHF), 2006). In 2006, research conducted on educational attainment found the proportion of Vietnamese with less than a high school diploma was twice as much as Asians as a whole (38% versus 19%), and subsequent research showed minimal improvements in the two years following this initial investigation (27% versus 6-15%) (Asian and Pacific Islander American Health Forum (APIAHF), 2006; Barnes, Adams, & Powell-Griner, 2008). With regards to health insurance coverage, Vietnamese may fare better than other SEA groups, with 17.9% uninsured, but they were three times more likely, than Asians or the general U.S. population, to report not visiting a physician due to cost issues (Asian and Pacific Islander American Health Forum (APIAHF), 2006).

Cancer research on Vietnamese women is much more expansive in comparison to the previous three groups, and this difference may be attributed to their larger population size and researcher interests. A 2004 study by Burke and colleagues suggested that cervical cancer incidence rates were highest among Vietnamese American women than any other racial/ethnic group, which subsequent studies attributed to lower screening rates (Burke et al., 2004; Kagawa-

Singer et al., 2007; Taylor et al., 2004). Breast cancer also remains as one of the top five cancer sites among Vietnamese women (Asian and Pacific Islander American Health Forum (APIAHF), 2006). Factors associated with higher breast and cervical cancer incidence rates and lower screening rates were the result of lack of access to regular sources of care, limited education and knowledge about screenings, and barriers related to cultural sensitivity and comfort level (Gor, Chilton, Camingue, & Hajek, 2011; Ma, Toubbeh, et al., 2009; McPhee et al., 1997; Pourat et al., 2010; Taylor, Nguyen, Jackson, & McPhee, 2008; Yoo, Le, Vong, Lagman, & Lam, 2011).

These findings suggest that breast cancer data is still lacking on the four SEA groups of interest and the paucity of available information limits the ability of researchers and community advocates to promote or replicate evidence-based programs to improve the health and well-being of this underserved population. The background demographic information (e.g. educational attainment, poverty rates, and refugee background of 3 out of 4 groups) on SEAs emphasized the variety of barriers and challenges encountered by this population. More specifically, the limited data on SEAs highlights the lack of ability within the U.S. health care system to address the health care access and utilization issues faced by this immigrant population, not to mention their inability to properly access health care services as a result of limited cancer related resources appropriate for these groups. The differences in health risk profiles among each ethnic group, when compared to the larger Asian and U.S. population, may have also exacerbated the disproportionate burden of cancer among these SEA groups such that these groups may encounter more barriers in accessing care due to LEP and cultural barriers. Thereby making a compelling argument for further investigation.

1.2 – Organizational Overview of AANCART

The degree objective for this dissertation study involves the identification of a problem of interest for an organization and the environment in which the organization interacts. The Asian

American Network for Cancer Awareness, Research, and Training (AANCART) is a grant-funded program expressly focused on reducing cancer health disparities among AAs and serves as an entity for this dissertation study to inform this group on how a major AA program can contribute to and improve the availability of cancer care resources and services for AAs in the United States.

1.2.1 Importance of PNPs Within the Organization

According to the Agency for Healthcare Research and Quality (AHRQ), a “patient-centered model” involves the active participation of patients in managing their own care, while health care professionals counsel and provide advice on the services needed to maintain the individual’s health (Agency for Healthcare Research and Quality, 2002). As the movement for patient-centered care increases, AANCART is in a key position to further this effort for AAs through its mission to reduce cancer health disparities among AAs within its diverse set of multi-level projects. Although the NOA was awarded through the Community Health Centers of the Health Resources and Services Administration (HRSA), AANCART has the capacity to identify and work with AA communities that would most benefit from the establishment of PNPs, as well as organizations armed with the natural proclivity to bring key issues affecting marginalized communities to the forefront, especially in regards to the distribution of resources and services for AAs. At the policy level, AANCART has the capability to affect policy change by generating evidence-based data as a national center to reduce cancer health disparities.

Results from this dissertation study will inform AANCART’s outreach core of the specific stage(s) in the cancer continuum where PNPs could provide the greatest contribution to improving access and quality of care for AA women with breast cancer. More specifically, assuming PNPs are found to be of value, study findings may assist with the development of a policy initiative to enable providers and stakeholders to address the gaps in services where guidance from patient navigators, trained to work with AA women screened through community-based programs and newly diagnosed AA women, would be most advantageous. This would be especially beneficial for those in health care facilities that serve the AA community but do not have culturally sensitive and skilled advocates.

1.2.2 History

AANCART was established in 2000, under the direction of Dr. Moon Chen, Jr. at the University of California, Davis, to reduce AA cancer health disparities. AANCART's first cycle of funding (2000-2005) was focused on building infrastructure, establishing partnerships, and formulating grant-funded research. In the second cycle of funding (2006-2010), AANCART continued to build its infrastructure by supporting community based participatory research (CBPR), education and training, fostering CBPR training, and further establishing the network as a credible and sustainable Community Networks Program (CNP) (M. S. J. Chen, Tong, & Dang, 2011). Under NCI's Center to Reduce Cancer Health Disparities-CNP, AANCART received its most recent award in 2011, a 5-year, $5.6 million grant to serve as the National Center for Reducing Asian American Cancer Health Disparities (Asian American Network for Cancer Awareness Research and Training, 2011).

Additionally, AANCART continuously expands its reach and creates mechanisms to reduce the burden of cancer among AAs by developing programs and resources, such as the Asian and Pacific Islander Cancer Education Materials (APICEM) web tool. A collaborative effort between AANCART and the American Cancer Society, APICEM was launched in 2006 to provide health care practitioners with a portal and a searchable online database for cancer education materials, in a variety of Asian languages, for their Asian and Pacific Islander patients (National Cancer Institute, 2006). The intent of APICEM was not only to serve as a resource for providers, but to offer a mechanism for tackling the language and cultural challenges experienced by non-AA health care providers to effectively educate and communicate with vulnerable AA communities.

1.2.3 Mission

As a network comprised of five sites and four cancer centers, AANCART's mission is **"to reduce cancer health disparities by conducting community-based participatory education, training, and research by, for, and with Asian Americans."** It is charged with three primary goals: 1) Sustain a network among the different regions in order to catalyze cancer education for AAs, 2) Establish research training programs to address AA cancer health disparities, and 3) Process and impact data to document the extent to which cancer health disparities are reduced among the six targeted AA subgroups (Asian American Network for Cancer Awareness Research and Training, 2011; M. S. Chen, Jr., 2005a).

1.2.4 Structure

As a multi-site network in which the combined population is approximately one-third of all AAs in the U.S., AANCART has focused, for the 2011-2015 period, specifically on assessing and reducing cancer risks among Americans of Chinese, Filipino, Hmong, Korean, and Vietnamese ancestry, within four regions of the United States: Sacramento, California (Hmong community); San Francisco, California (Vietnamese and Chinese communities); Los Angeles, California (Korean community); Honolulu, Hawaii (Filipino community) (Asian American Network for Cancer Awareness Research and Training, 2011).

The AANCART Center, as a U54 grant mechanism, has five constituent groups: 1) Steering Committee, which serves as the executive body by establishing the organization's priorities, 2) Community Advisory Group, which consists of prominent lay, clinical, and academic leaders who offer the Steering Committee recommendations, 3) Consortium Members, which involves organizations throughout the U.S. West Coast, 4) External Advisory Board, which functions to evaluate AANCART progress towards meeting its specific aims, strengthening its planned efforts, and providing recommendations for future plans, and 5) Core teams, which are further divided into Administrative, Outreach, Research and Training cores, each charged with different foci (Asian American Network for Cancer Awareness Research and Training (AANCART), 2011).

1.3 – Dissertation Aims & Hypotheses

This dissertation addresses the following question: How does enactment of policy influence the availability of patient navigation programs and improve access to cancer care services? The dissertation is comprised of two distinct studies that explore the needs of SEA women with breast cancer. The approach included: 1) quantitative study, to assess the magnitude and frequency of available patient navigation programs in the Los Angeles and Orange County areas, and 2) qualitative study, to explore the perceptions of practitioners exposed to patient navigators. This study involved the use of multiple datasets. For the quantitative study, facility level data collected through two surveys (Short Telephone Questionnaire and Facility Survey) and tumor registry data from the Los Angeles Cancer Surveillance Program. For the qualitative analyses, secondary data from transcripts obtained from a Breast Cancer Research Program funded study were evaluated. These datasets were used to the address the primary research question and study aims.

1.3.1 Legislation Effect on Quality of Care (Study 1)

The first study examined whether the enactment of the NOA signaled a health care system recognition of the contribution of PNPs as a viable tool to improve access to cancer care services and quality of care for SEAs. It also examined whether the NOA had an impact on improving the timeliness between diagnosis and treatment. This study hypothesized that the NOA increased the availability of PNPs and improved access to and quality of care for SEAs.

Access to care was measured by examining time to surgery after diagnosis, while quality of care was measured by investigating the type of cancer care resources and services available for SEA women. The study collected facility level data from PNP coordinators and navigators from Los Angeles and Orange County hospitals through surveys developed from the Promoting Access on Research Implementation in Health Services (PARiHS) framework (described in Chapter 2). This study also used secondary data from the Los Angeles Cancer Surveillance Program of approximately 1300 SEA breast cancer patients residing in Los Angeles and Orange counties between 2000-2010. Together, the study measured the effect of legislation on the availability and quality of breast cancer care services for SEA women with the potential impact of improving AA breast cancer survival rates.

1.3.2 Practitioner Perceptions of Patient Navigation Programs (Study 2)

The second study assessed whether practitioner perceptions of PNPs and their experiences with navigators supports the need for the adoption and integration of PNPs into the U.S. health care system. This study used secondary data, consisting of transcripts from a community-based participatory research (CBPR) study led by Dr. Tu-Uyen N. Nguyen. The goal of Dr. Nguyen's research was to document the work and processes performed by community-based health navigators to help SEA women access and utilize breast health services, with the long-term objective of developing a formal training curriculum for community health navigators. In this study, an ethnographic, qualitative approach was applied to explore the experiences and views of practitioners, as it relates to the use of patient navigators among SEA breast cancer patients. Interview transcripts were examined to investigate whether patient navigators were instrumental in minimizing patients' obstacles to receipt of timely care and improving patient-provider communication. Key concepts from the PARiHS framework (i.e. context, facilitation and evidence) were also used during the analysis of the transcripts in order generate hypotheses to understand how PNPs were perceived by practitioners, how PNPs functioned within the health care system, and if patient navigation services ameliorated the challenges of accessing care.

1.4 – Innovation & Contributions of Dissertation Research

An imperative of the Patient Protection and Affordable Care Act (ACA) is a movement towards improving health systems delivery models. This dissertation, examining PNPs for an underserved population, is one of the first studies to attempt to understand the value of PNPs, in relation to the level of adoption, at the system level. The findings from this dissertation could inform policies about the significance of PNPs in helping immigrants obtain quality cancer care services and improve their access to and appropriate use of care by informing stakeholders about how the adoption and integration of PNPs into health services may provide an evidence base for research advocacy networks of the utility of patient navigation services in the timely receipt of cancer treatment. Few studies have examined the value of PNPs in relation to investigating the delays between time to diagnosis and start of treatment. Study results could also inform practitioners about the benefit of supporting the integration of PNPs into the health care system to improve patient-physician communication in the care of breast cancer patients.

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CHAPTER 2

Conceptual Framework

2.1 – Measures on Delays of Care

Without proper assistance and guidance, cultural and linguistic challenges can hinder Southeast Asian (SEA) women from seeking care at each stage of the cancer care continuum. An assessment of the varying degrees of delays in receipt of care must be conducted to better understand the value of patient navigation programs (PNPs) and to highlight the areas within the continuum, from point of diagnosis, to and through treatment, where patient navigators would be most effective in assisting underserved communities. An important factor that may be contributing to the differences in the quality of breast cancer care received among SEA groups, such as Cambodians, Laotians, Thais and Vietnamese, may be attributed to delays in the receipt of care. Cultural and linguistic barriers are the primary elements adding to delays in obtaining breast cancer care among SEAs, while lack of knowledge about the U.S. health care system may serve as another layer deterring women from accessing the health care services they need.

One of the earliest studies to investigate delays in cancer care classified "delay" into two categories, patient delay and provider delay, and found that within a meta-analysis of patient delay studies, an estimated 34% of women with breast cancer delayed seeking care for 3 months or more, while data on provider delay was found to be limited (Facione, 1993). In 2005, a more recent study by Bish and colleagues defined "delay" or "total delay" in breast cancer care as "the time between a woman first noticing a breast cancer symptom and receiving treatment" (Bish, Ramirez, Burgess, & Hunter, 2005). This definition was expanded further by describing "patient delay" as the period in time between "first notice of a sign or symptom of illness and initial medical consultation," and defining "provider delay" as the period in time between "initial medical consultation and definitive treatment" (Bish et al., 2005).

In another early study, elements of patient delay was identified as fear and denial, lack of cancer information, and financial limitations (Love, 1991). Later investigations suggest additional reasons for delay in seeking care at symptomatic presentation were associated with psychological factors (i.e. fear of a cancer diagnosis, belief that symptoms were not serious, belief that symptoms would resolve itself) rather than demographic predictors (i.e. age, marital status, ethnicity), and further inspection can be extended to look at factors associated with short delays (i.e. a time period of 4 weeks or more) and long delays (i.e. a time period of 3 months or more) (Bish et al., 2005; Nosarti et al., 2000). Non-cancer related studies attribute patient delays to the same psychological factors of fear, denial, and belief that symptoms would resolve without medical attention (Calder, Gao, & Simmons, 2000; Dracup, McKinley, & Moser, 1997; Meischke, Ho, Eisenberg, Schaeffer, & Larsen, 1995), while short delays were indicated by intensity of symptoms and ability to actively seek care (Noureddine et al., 2006). The study by Nosarti and colleagues found that long delays were more closely associated with psychological factors and highly attributed to the fear of cancer, as well as preference for a female consultant, while health-system delay was the result of patient delay and missed appointments, which may be attributed to incorrect addresses by administrative staff (Nosarti et al., 2000).

The few studies examining patient delay among ethnic communities found most of the factors associated with delay were similar across racial groups (African Americans, whites, Latinos and Chinese) but unique to Chinese women was the delay in seeking care due to a "sense of invulnerability to breast cancer" and "a linking of cancer to tragic luck" (Facione, Giancarlo, & Chan, 2000). Other studies that investigated delays in receipt of care between diagnosis and treatment among multiple insured ethnic groups of women diagnosed with breast cancer found African American women to experience significant delays (lasting more than 60 days) in diagnosis, treatment and clinical care regardless of stage at diagnosis (Gorin, Heck, Cheng, & Smith, 2006; Lund et al., 2008).

Although publications on patient delay are extensive, the opposite can be said for research on provider and health-system related delays. A literature review that examined delays in cancer care, found provider delays were associated with factors such as the general practitioners ability to recognize symptoms, referral delays, and misdiagnosis of younger patients due to the belief that they are at lower risk for cancers (Almuammar, 2010; Ramirez et al., 1999). Additionally, patient delays, such as noncompliance, contributed to provider delay between diagnosis and treatment (Bedell, Wood, Lezotte, Sedlacek, & Orleans, 1995).

As previously discussed, many of the factors identified with delays between diagnosis and treatment were primarily due to patient help seeking behaviors and beliefs, such as fear and denial, perceived severity of symptoms, knowledge of the illness, and perceived ability to seek care, as well as provider and health-system delays associated with symptom assessment, referrals and perceptions of lower risks for younger patients. Aspects related to patient delay can be addressed through the aid of patient navigators, but additional investigation on provider and health-system delays are needed to offer insight on the usefulness of PNPs in decreasing delays and improving access to care for patients with breast cancer.

2.2 – Conceptual Framework

The conceptual model of Patient Navigation Integration (Appendix - Figure 2.1) was developed for Study 1 to showcase the diverse patient level challenges and health care system factors that may contribute to delays in seeking care between the point of diagnosis and initiation of treatment. Examples of patient or individual level factors include scheduling delays associated with the inability to make health care appointments or opportunity costs, such as loss of income due to time off work to attend medical appointments. Health care system factors can include provider characteristics, such as gender and ethnic background, or practice patterns associated with the number of patients a practitioner sees per day and whether clinicians accept Medicaid and Medicare recipients. Both patient level and health system factors can occur simultaneously at various points on the cancer care continuum, however, the period between diagnosis and treatment is an integral point in determining survival. This model highlights how the Patient Navigator Outreach and Chronic Disease Prevention Act (NOA), as an institutional tool to initiate the development and implementation of PNPs, served to moderate access to care for SEAs (compared to non-Hispanic whites) between the stages of diagnosis and treatment in the cancer continuum. This model was also applied to Study 2 and will focus on the practitioner and navigator perceived barriers to receipt of timely care during the interval between diagnosis and first course of treatment.

The Promoting Action on Research Implementation in Health Services (PARiHS) framework describes the multiple components needed for successful implementation of an intervention and indicates that evidence, context, and facilitation are the most important pieces that determine how well a program will be implemented (Figure 2.2) (Kitson et al., 2008). Kitson and colleagues describe successful implementation (SI) as a function (f) of the nature and type of evidence (E), the qualities of the context (C) in which the evidence is being introduced, and the way the process is facilitated (F) such that: SI = f (E, C, F) (Kitson et al., 2008). To elaborate on these three domains, Helfrich and colleagues describe "evidence" as the resources, clinical experience, professional knowledge and patient preferences or experiences that evolves from local practice, such that the source of information is one of the key factors for informing stakeholders about the success of a program (Helfrich, Li, Sharp, & Sales, 2009). “Context”, as a second factor, involves the background information on the organization and is associated with essential aspects, such as the attitudes and beliefs of organizational members, the decision-making processes of the organizational leaders, and the mechanisms for obtaining feedback and assessing program quality (Helfrich et al., 2009). “Facilitation” is described as the ability of the organizational members and leaders to understand the program needs and their responsiveness in implementing the necessary changes to achieve program success (Helfrich et al., 2009). The PARiHS framework could help frame the evidence to design PNPs and achieve PNP success.

The Andersen General Model of Total Patient Delay was adapted to conceptualize delay intervals occurring between phases of decision-making (Figure 2.3) (Walter, Webster, Scott, & Emery, 2011). It was applied in this study to showcase the access points in the cancer continuum where decision-making delays could affect timely receipt of health care services and how patient navigators could be utilized to improve timeliness to each phase of care.

Walter et al.’s refinement of B.L. Andersen’s General Model of Total Patient Delay for cancer care and the Promoting Action on Research Implementation in Health Services (PARiHS) framework were adapted for this descriptive study on program adoption (Kitson et al., 2008; Walter et al., 2011). These two models, along with the Cancer Continuum, guided the development of questions to assess whether culturally synchronous (language and cultural knowledge) PNPs were available at health care facilities that served the SEA cancer patients, in Los Angeles and Orange Counties. The conceptual framework presented in this study is designed to support the idea that adoption of PNPs at the system level could assist patients in accessing cancer care services at each stage of the cancer continuum (Figure 2.4). For this study, the period between diagnosis and treatment will be examined to determine how PNPs may be instrumental in addressing the challenges associated with SEA women seeking cancer care services.

FIGURE 2.1
Conceptual Model of Patient Navigation Integration

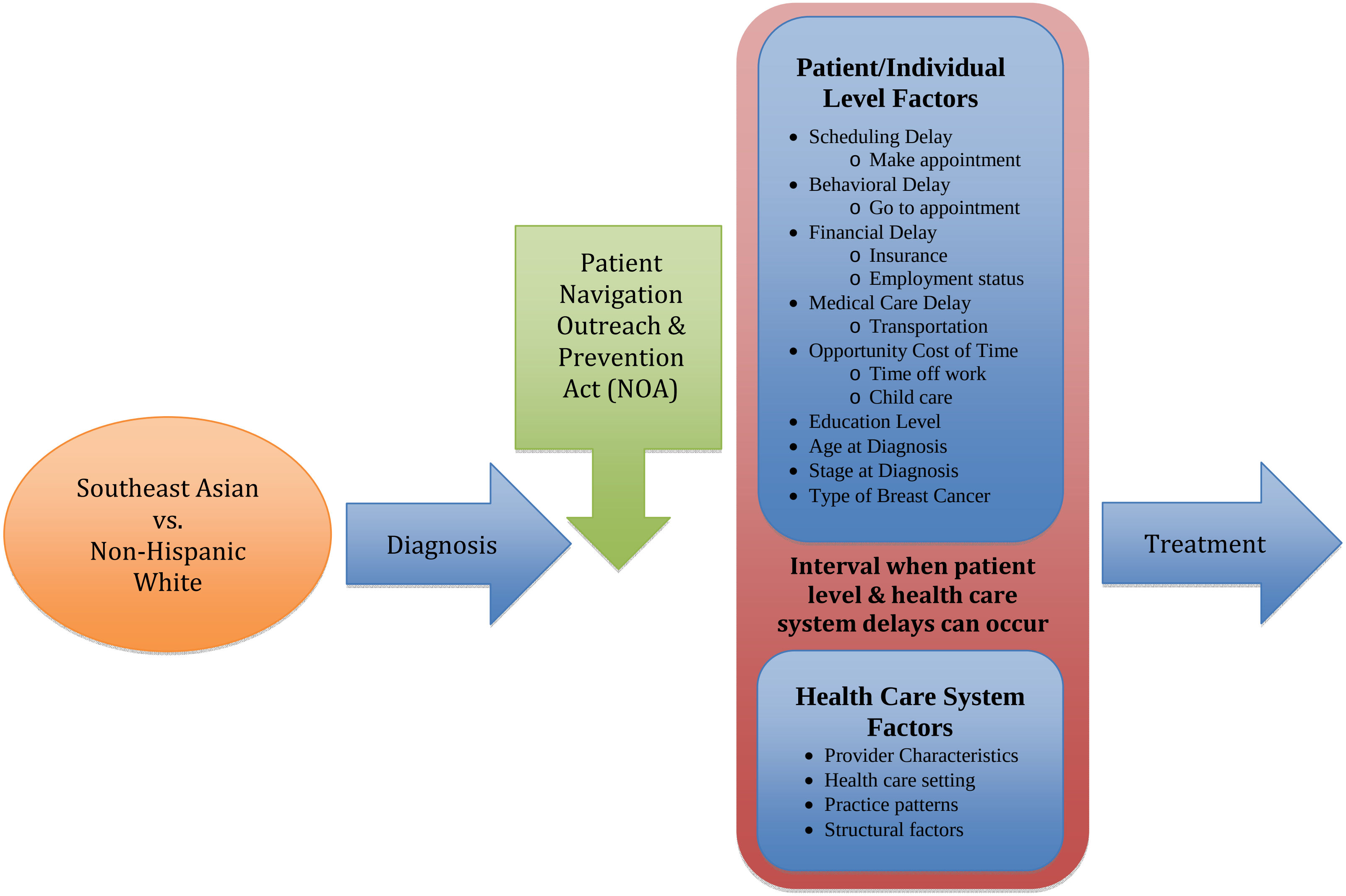
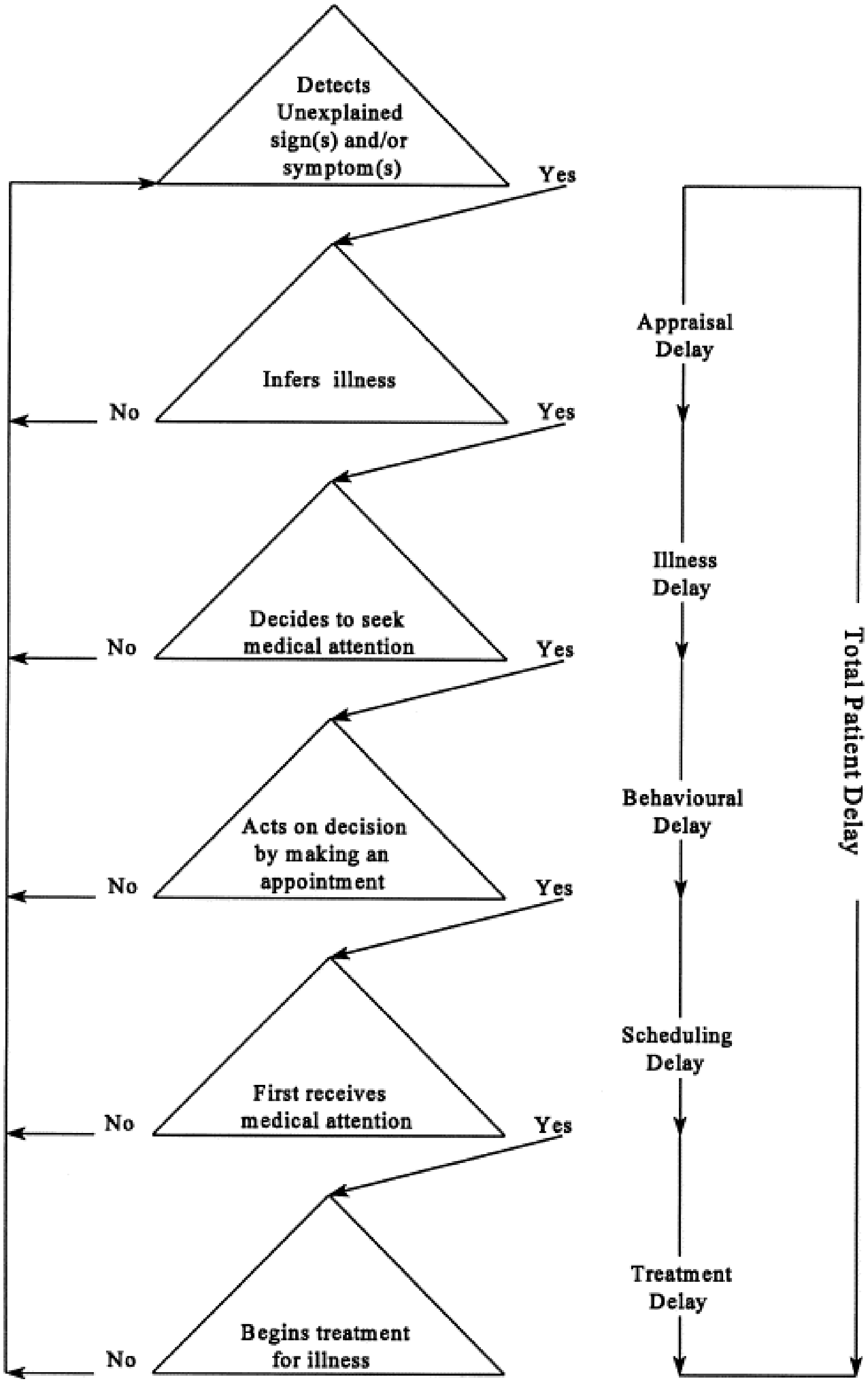


FIGURE 2.2
Promoting Action on Research Implementation in Health Services (PARiHS)

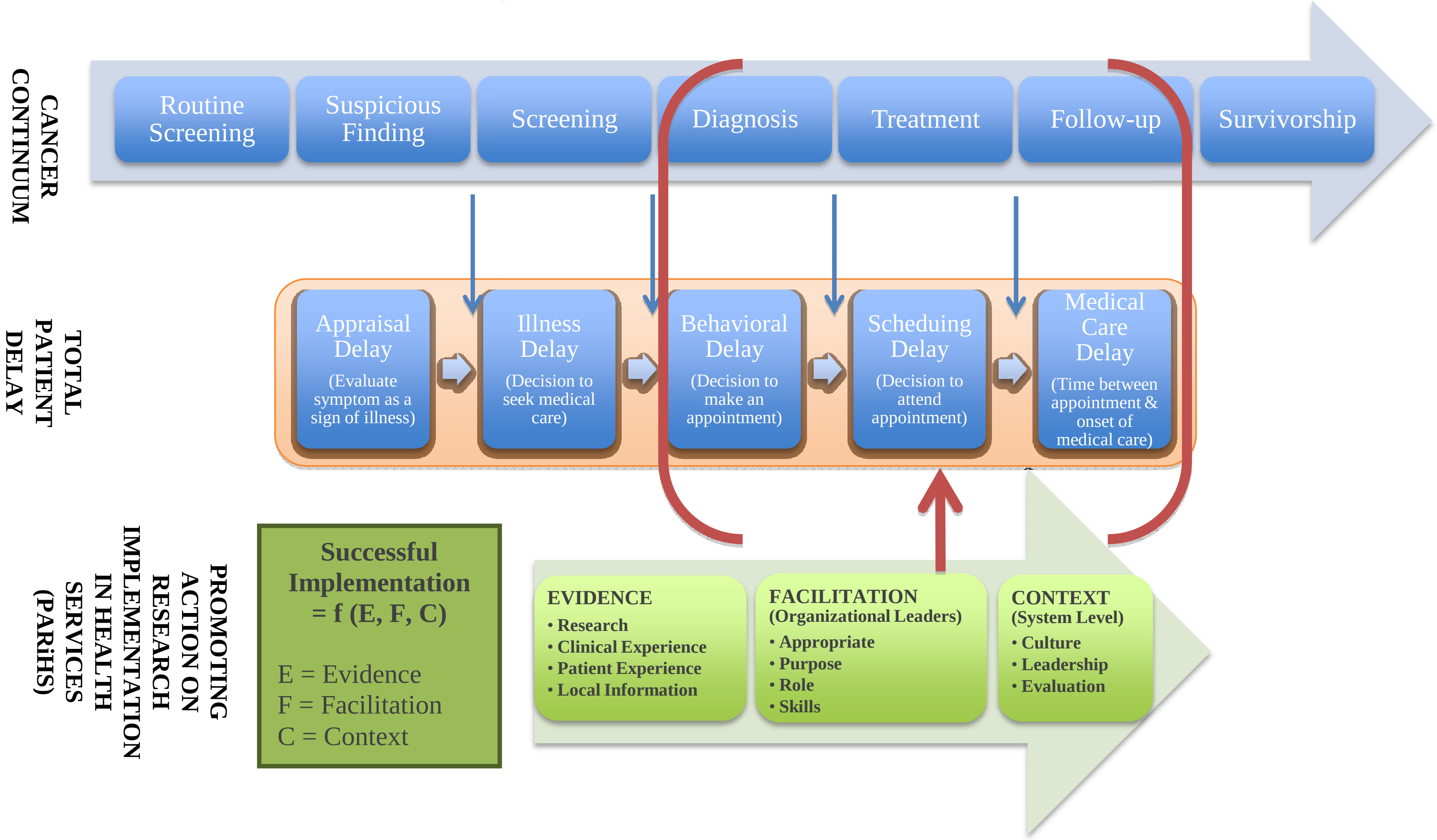
Source: *Kitson, A. L., Rycroft-Malone, J., Harvey, G., McCormack, B., Seers, K., & Titchen, A. (2008). Evaluating the succe implementation of evidence into practice using the PARiHS framework: theoretical and practical challenges. Implement Sci, 3, 1*

FIGURE 2.3
Andersen General Model of Total Patient Delay



Source: *Walter, F., Webster, A., Scott, S., & Emery, J. (2011). The Andersen Model of Total Patient Delay: a systematic review of its application in cancer diagnosis. J Health Serv Res Policy.*

FIGURE 2.4
Conceptual Framework Across Cancer Continuum



Sources: *Total Patient Delay = Walter, F., Webster, A., Scott, S., & Emery, J. (2011). The Andersen Model of Total Patient Delay: a systematic review of its application in cancer diagnosis. J Health Serv Res Policy.*

PARiHS = Kitson, A. L., Rycroft-Malone, J., Harvey, G., McCormack, B., Seers, K., & Titchen, A. (2008). Evaluating the successful implementation of evidence into practice using the PARiHS framework: theoretical and practical challenges. Implement Sci, 3, 1.

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CHAPTER 3

Legislation Effect on Quality of Care (Study 1)

3.1 – Abstract

Purpose: Cultural and linguistic barriers are often contributing factors in accessing health services at different points on the cancer care continuum. Proper assistance and guidance from patient navigators may serve as a mechanism for addressing delays in utilization and receipt of cancer care services. This study examines whether a policy, the Patient Navigator Outreach and Chronic Disease Prevention Act (NOA) in 2005, served as a catalyst for increasing the availability of cancer patient navigation programs (PNPs) in Los Angeles and Orange County health care facilities who treat Southeast Asian (SEA) breast cancer patients and if the availability of patient navigation services at a facility had an impact on quality of care by improving timeliness between cancer diagnosis and treatment.

Methods: Hospitals which treated the largest proportion of SEA patients in Los Angeles and Orange County were selected. A hospital administrator from each facility was surveyed by mail or telephone to assess 1) facility awareness of the NOA, 2) the role of the policy in establishing PNPs, and 3) the availability and quality of established PNPs in providing cancer care services to women with breast cancer. The Facility Survey data was used to categorize each hospital as PNP-Available (PNPs established 2006-2010), or PNP-Unavailable (no established PNPs and PNPs created after 2010). Regional registry data was used to obtain aggregated patient data in the surrounding census tracts of each facility, which were grouped according to the availability of PNPs. The outcome measures of median number of days between diagnosis and initial surgical treatment of breast cancer, and the percent receiving surgery within 30 days after diagnosis, were compared for patients living in the surrounding areas of facilities according to

their NOA group, and between the time periods before and after the enactment of the NOA legislation.

Results: Primary data collected through facility surveys informed the NOA categorization of 13 facilities (4 PNP-Available and 9 PNP-Unavailable). Survey responses assessed the impact of the NOA, highlighted the complexity and diversity of available PNPs, and provided information pertaining to the context, facilitation and evidence for establishing and implementing PNPs. Analyses of registry data showed no differences in time to treatment between PNP-Available and PNP-Un-available facilities, however median time to treatment increased in all facilities between the pre- and post-NOA time periods. All four PNP-Available hospitals provided navigation services between diagnosis and treatment. One out of four PNP-Available facilities provided linguistic and cultural services to a SEA group. Most facilities noted that patient navigation services were granted upon request and mechanisms were in place for referring patients to additional resources.

Conclusions: This descriptive study showed that the NOA legislation was not directly associated with the development of PNP in most facilities studied. Availability of administrative support, secured funding, and institutional certification requirements may have been key factors that led to the adoption of PNPs in PNP-Available facilities. An ecologic study of the quality of care for breast cancer patients in facility catchment areas did not indicate an association with time to treatment in relation to the availability of PNPs in nearby facilities. Receipt of surgery within 30 days was better for SEAs than NHWs at both pre- and post-NOA periods in PNP-Available and PNP-Unavailable facilities. Time to treatment did not improve between pre- and post-NOA in facilities with PNPs. A larger sample of facilities with PNPs and analysis of time to treatment for patients actually using the PNP versus those not using a PNP may provide a better assessment of the association between PNPs and quality of care measures, and would allow for control of other confounding factors that may impact treatment delay. Patient reported measures, such as satisfaction with care, should also be considered in future evaluations of PNPs.

3.2 – Introduction

Ethnic specific research on Asian American (AA) women is limited and the available data points to low screening rates, which contributes to late stage diagnosis and delays in receipt of treatment modalities (Gomez et al., 2010; Kagawa-Singer & Pourat, 2000; Kagawa-Singer et al., 2007; Kwong, Chen, Snipes, Bal, & Wright, 2005; Tanjasiri, Kagawa-Singer, Nguyen, & Foo, 2002; Wang, Fang, Tan, Liu, & Ma, 2010). Poor breast cancer health outcomes of Asian immigrant subgroups are also evident when subgroup information is disaggregated from the overall AA results and these health disparities are likely due to the lack of information, language barriers, and lack of resources available for specific communities (Chen, Diamant, Kagawa-Singer, Pourat, & Wold, 2004; Gomez et al., 2010; Lauderdale & Huo, 2008; Srinivasan & Guillermo, 2000).

Many of the barriers and challenges encountered by Southeast Asians (SEAs) in accessing cancer care services could be addressed by patient navigation programs (PNPs). Research conducted by Nguyen and colleagues on community health navigators among Cambodians and Laotians found that both communities encountered social, educational, economic, and political barriers, but at various levels due to differences in community infrastructures and resources (Nguyen, Tanjasiri, Kagawa-Singer, Tran, & Foo, 2008). This study outlined the steps needed to navigate one woman from point of contact to receipt of a screening exam and highlighted that the amount of time and effort required averaged between 3 and 25+ hours (Nguyen et al., 2008). More importantly, the navigation services given were found to not only provide informational and instrumental support, but were effective in getting

Cambodian and Laotian women screened for breast and cervical cancers as a result of the navigator's empathy and respect for the women and their understanding of the community's resources (Nguyen et al., 2008). This study suggests the advantages and utility of patient navigation services in improving screening, while other studies point to the benefit of navigators in improving follow-up to abnormal mammograms and reducing delays in diagnostic resolution (Battaglia, Roloff, Posner, & Freund, 2007; Ell, Vourlekis, Lee, & Xie, 2007; Ferrante, Chen, & Kim, 2008; Maxwell, Jo, Crespi, Sudan, & Bastani, 2010; Psooy, Schreuer, Borgaonkar, & Caines, 2004). Yet, with the growing amount of studies verifying the benefits of patient navigation services and care coordination programs between screening and diagnosis, the availability of PNPs is still limited. This issue is particularly evident with the lack of programs targeting ethnic specific communities experiencing cancer care disparities, primarily during the post-diagnosis phase.

Additionally, literature investigating the role of PNP in reducing time between diagnosis and treatment is non-existent and research examining timely receipt of care between the diagnosis and treatment phase of the cancer continuum among AAs is limited. To date, one study investigated delays in breast cancer diagnosis and treatment among multi-ethnic (non-Hispanic whites, African American, Hispanic and Asian/Pacific Islander) Medicare recipients (Gorin, Heck, Cheng, & Smith, 2006) and another study examined the role of a multi-site PNP in reducing delays in breast cancer diagnosis among non-Hispanic whites (NHWs), non-Hispanic blacks, and Hispanics (Hoffman et al., 2012). The aggregate number of Asian/Pacific Islanders in the study by Gorin accounted for 3.2% (n=1,617) of the entire study sample (n=49,865), while the study by Hoffman did not distinguish the number of AAs (if any) patients who participated in the research.

3.2.1 Patient Navigator Outreach and Chronic Disease Prevention Act

The Patient Navigator Outreach and Chronic Disease Prevention Act (NOA) was signed into law in 2005 with the goal to "evaluate approaches to developing and implementing patient navigator services to improve health care outcomes for individuals with cancer and other chronic diseases, with a specific emphasis on health disparities populations" (Dept. of Health and Human Services, 2012). As a demonstration grants program, NOA funding was allocated to: 1) train individuals who have direct knowledge of the communities they serve, 2) identify and help patients overcome health care system barriers, 3) develop and operate PNPs, and 4) promote health education and to encourage the use of primary care services among populations with the greatest health care disparities (Dept. of Health and Human Services, 2013). In relation to this study, the purpose of the NOA is to assess if navigators "reduced barriers to access to care" and if PNPs "improved health care outcomes" (Urrea, 2009).

3.2.2 Policy and Practice Questions

This dissertation study examined time to treatment and the role of PNPs in the U.S. health care system, especially in institutions in Los Angeles (LA) and Orange Counties (OC) serving SEA women diagnosed with breast cancer. More specifically, this study investigated whether the enactment of the NOA served as a successful cause-agent in improving treatment delay after diagnosis among breast cancer patients through the development and implementation of PNPs. Findings from previous studies on PNPs informed the development of the study surveys, which collected descriptive data on PNPs.

As previously described (Chapter 2), the Promoting Action on Research Implementation in Health Services (PARiHS) framework utilizes three core elements (evidence, context and facilitation) to assess the successful implementation of a program or research (Kitson et al., 2008). Evidence can be derived from four sources, such as research, clinical experience, patient preference and routine information from local practice; context stems from three components, such as organizational culture, leadership and evaluation; while facilitation is based on the notion of human activity, which involves helping individuals/teams understand what needs to be changed and how to do it (Helfrich, Li, Sharp, & Sales, 2009). Both Kitson and Helfrich describe the PARiHS model as a mechanism for assessing and evaluating the readiness of an organization to successfully implement a specific evidence-based program into practice (Helfrich et al., 2009; Kitson et al., 2008). Based on the PARiHS model, the context of patient navigator experiences, the role of the program facilitator, and information regarding the facilitation of PNPs illuminated the development of the survey questions.

The policy and practice questions for this study involved an assessment of the effect of a legislative act:

Q1) Were health care facilities, with an available PNP and who serve SEAs, aware of the NOA?
Q2) Did the NOA have a role in establishing a PNP in the facility? How much of a role? Were there other sentinel factors?
Q3) What was the availability and quality of the PNP in facilities that have PNPs, in terms of serving SEAs and providing cancer care services?
Q4) Did time to treatment, on average, improve after the enactment of the NOA for SEAs? How did this compare to a benchmark group that may not be as reliant on patient navigators?

A descriptive analysis of two surveys was performed to assess the role of the NOA and the availability of PNPs, among health care facilities serving SEAs. A quantitative analysis of regional cancer registry data was conducted to investigate the association of available of PNPs in nearby facilities on median time to treatment among patients residing in census tracts within a 1-mile radius of a facility, according to the availability of a PNP at the facility and between two time periods: pre-NOA (2000-2005) and post-NOA (2006-2010).

3.3 – Materials and Methods

3.3.1 Study Design

This dissertation study incorporated two study designs for the two primary outcome measures: 1) did the NOA have a role in the establishment of PNPs and 2) did time to treatment improve after the enactment of the NOA. As noted, the NOA was enacted on June 29, 2005 (U.S. Government Printing Office, 2005). Two time periods, pre-NOA (2000-2005) and post-NOA (2006-2010), were investigated to determine whether hospitals had a patient navigation system in place pre- and post-NOA (see Study Design 1).

Study Design 1

Pre-NOA 2000-2005	NOA	Post-NOA 2006-2010
O_1	X_1	O_1

O_1 = Availability of PNP; X_1 = policy enactment

After assessing the availability of PNPs, these facilities were grouped into two categories: PNP-available and PNP-unavailable (see Study Design 2). PNP-available facilities were classified as institutions that developed PNPs during the post-NOA time period. PNP-unavailable facilities were characterized as institutions that did not implement a PNP during the pre- or post-NOA time periods, as well as facilities that established a PNP after the NOA time period of 2006-2010.

Study Design 2

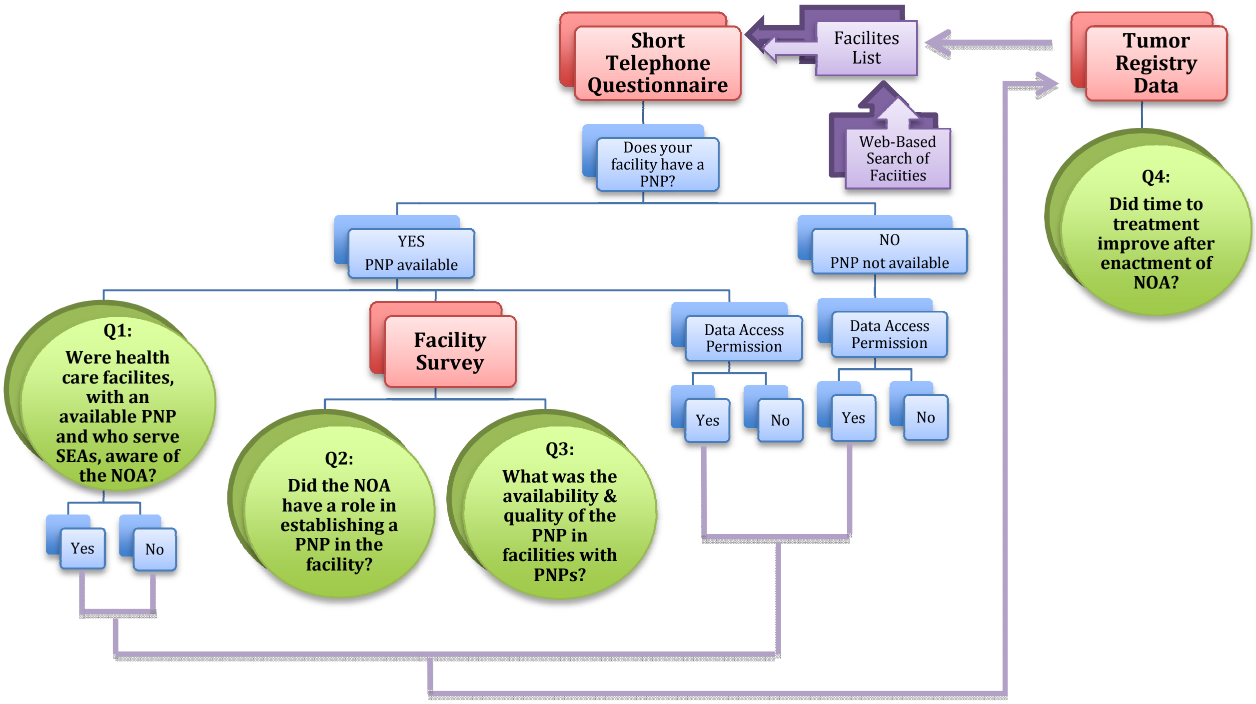
	Pre-NOA 2000-2005	**PNP**	**Post-NOA 2006-2010**
PNP-available	O_2	X_2	O_2
PNP-unavailable	O_2		O_2

O_2 = Availability of PNP; X_2 = policy enactment

3.3.2 Data Sources

A total of three data sources were used in this study to assess the role of the NOA on the establishment of PNPs and to examine how the availability of PNPs affected time to treatment at these hospitals: 1) Short Telephone Questionnaire, 2) Facility Survey, 3) Tumor Registry Data.

Figure 3.1 – Data Source and Research Question Map



A human subjects research application was submitted to the University of California, Los Angeles (UCLA) Office of the Human Research Protection Program (OHRPP) to obtain permission to contact health care facilities, administer surveys (Short Telephone Questionnaire and Facility Survey), and to send the data access request. The UCLA-OHRPP internal review board granted approval January 14, 2013 with protocol identification number 12-001886.

3.3.2.a – Facilities List

Hospitals that served at least 2-3% of SEA women diagnosed with invasive breast cancer in LA and OC during two time periods (2000-2005 and 2006-2010) were identified through the Los Angeles-Cancer Surveillance Program (LA-CSP) or Tumor Registry. These hospitals (n=20) were used to create the Facilities List. Additional hospitals (n=4) used for comparison of Non-Hispanic Whites was identified through a web-based search as having PNPs in the LA and OC areas, but not associated with serving a higher proportion of SEAs, were also added to the Facilities List, generating a total of 24 hospitals. The web-based facilities were included to produce sufficient numbers of facilities with PNPs for comparison and to allow for racial/ethnic group comparison between hospitals. The Facilities List was used to gather the data for Study Design 1. The data source and data collection process for the identification of hospitals are detailed in Appendix 3.1-Facilities List.

3.3.2.b – Short Telephone Questionnaire

The Short Telephone Questionnaire (see Appendix 3.2) consisted of six structured questions and functioned to obtain information associated with awareness of the NOA (Q1), the role of the NOA in establishing a PNP (Q2), and the quality of PNPs (Q3). Using the Facilities List, institutional contact information was obtained through a web-based search and these facilities were contacted. A total of 14 out of 24 (58%) facility representatives were reached and interviewed using the Short Telephone Questionnaire. The facility representatives contacted for the questionnaire included PNP coordinators and navigators from the selected LA and OC hospitals. These people were identified as individuals with knowledge about patient-centered programs, worked with breast cancer patients, or were familiar with PNPs at their institutions.

Each hospital on the Facilities List was contacted by phone, with two re-contact attempts, and an “Initial Script To Contact Facilities” (see Appendix 3.3) was used to: 1) call the institution to determine the best method of contact for personnel with administrative oversight of patient-centered service programs or PNPs, and 2) set a date/time for a phone meeting. Responses were collected on hard copies of the questionnaire, and data was entered into Microsoft Excel at the completion of the phone meeting.

Initial analysis of the Short Telephone Questionnaire was performed to: 1) assess if a facility had a PNP, 2) determine the year the PNP was established, if a program was available, and 3) determine PNP availability at the facility. The data obtained through the Short Telephone Questionnaire was used for Study Design 2.

3.3.2.c – Facility Survey

For facilities determined to have a PNP, the Facility Survey was conducted (see Appendix 3.4) to obtain basic information about the implementation of the PNP and the type of services offered. More specifically, the Facility Survey was used to obtain additional descriptive information about factors that contributed to the development of PNPs at each hospital (Q2) and to assess the quality of the PNPs in providing cancer care services, especially to SEAs (Q3).

At the end of the Short Telephone Questionnaire phone meeting, personnel at hospitals confirmed to have a PNP were asked to assist with two additional items: 1) the completion of the Facility Survey, which contained 19 close- and open-ended questions and 2) to respond to an email message (see Appendix 3.5) requesting for permission to access and review hospital specific data from the LA-CSP database (which was required for data release by the registry). Data access permission from key personnel at hospitals without a PNP was also requested in an effort to compare hospital specific data between the two facility-type groups.

The Facility Survey and data-linkage permission requests were sent by regular mail or electronically, and the data collection process is detailed in Appendix 3.6-Process for Administering Facility Survey and Permission Request. Two follow-up attempts were made for the Facility Survey and three follow-up attempts were made for the permission request. Data from the Facility Survey were entered into Microsoft Excel as they were received.

Analysis of the Facility Survey involved frequencies of responses from descriptive questions to assess and obtain a general understanding about existing PNPs in LA and OC. Responses were also examined to characterize the processes used by the PNPs, to distinguish the reasons for developing patient navigation services, and to identify barriers and challenges experienced by key personnel of existing programs.

3.3.2.d – Pilot Testing

Both surveys were sent to and pilot tested by key personnel from two health care facilities with existing PNPs. Pilot testers were affiliated with institutions not included in the Facilities List. Pilot testing of the surveys were conducted between late-January 2013 to mid-February 2013. Minor changes associated with the inclusion of additional check box options were incorporated into both surveys. The data collection process, which included the phone questionnaires, surveys and permission requests, was conducted between mid-February 2013 through May 2013.

3.3.2.e – Questionnaire Development

For reference, the PARiHS model served as a tool to guide the development of the questions for the “Original Facility Survey” (see Table 3.1). These questions were later divided and modified into the two surveys, which contributed to descriptive data about existing PNPs.

Table 3.1 - Original Facility Survey

PRIMARY QUESTION: ***Does your facility currently have a program or care coordination system in place to assist patients after receipt of a cancer diagnosis?***	
YES	**NO**
CONTEXT	
What was the impetus for establishing a program?	Are any mechanisms in place to assist patients if additional services are needed?
Who led the development of the program?	Do you offer any programs to assist cancer patients?
What positions did these leaders hold in the health care facility?	*(Same questions in YES column if a program is available)*
Who were the program supporters?	What were the reasons for NOT providing additional assistance mechanisms?
How are these program supporters associated with the health care facility?	Have you ever had a program? When? Why was it discontinued?
Did you receive any funding to support the program? What was the funding source? Do you have ongoing funding to support the program?	
When was the program established?	
Were the program leaders aware of the NOA?	
Was the NOA related to the establishment of the program?	

Who does the program target?	
How are patients identified?	
How are patients managed through this system?	
What types of services are provided?	
FACILITATION	
How are patient navigators identified?	Were there any barriers in the development of a patient assistance program? If yes, what were those barriers?
What are the requirements to become a patient navigator?	
Do your patient navigators receive any type of training?	
What type of training is required?	
Are PN services reimbursed by insurance companies?	
Are patient navigators paid? If yes, how are patient navigators paid?	
How did program leaders assist/help in the development of the program?	
What did program leaders do to encourage support for the program?	
What types of resources and/or tools did program leaders use during the development of the program?	
What actions contributed in better uptake of the program?	
EVIDENCE	
How many patient navigators do you have?	*(Modified questions in YES column if a program or care coordination system was available)*
How are patient navigators assigned or matched with a patient? Specific languages spoken?	
At what stage in the health care process are patient navigators assigned/matched with a patient?	
How many patients have been navigated through your system?	
Are there mechanisms to assess or evaluate the services provided by patient navigators?	
Are the services provided by patient navigators evaluated by patients, or providers, or both? If yes, how is feedback provided?	
Are there mechanisms to assess the health or progress of the patient? If yes, how is feedback provided?	
How many patients are assisted each year? How many are breast cancer patients? How many are South East Asian?	
Have the patients provided any feedback or comments regarding the program?	

Have you measured the effectiveness of the program in any way?	

3.3.2.f – Tumor Registry Data

Secondary data was obtained from the LA-CSP and used to: 1) identify hospitals accessed by a higher proportion of SEA breast cancer patients, 2) provide aggregated patient information from patients residing in census tracts surrounding each facility on NHW, Hispanics, and SEA (Cambodian, Lao, Vietnamese and Thai), female breast cancer patients in the LA and OC areas, and 3) investigate the time to treatment after diagnosis for SEAs and other groups among patients in catchment areas near PNP-available and PNP-unavailable facilities and in both facility groups before and after enactment of the NOA (Q4).

The LA-CSP serves as the population-based cancer registry for Los Angeles County. The registry became population-based in 1972 and complete incidence data for Los Angeles County are available from that year forward. As of 2014, the LA-CSP master file contains over 1.7 million records and some 41,000 incident cancers are added annually. The LA-CSP is a member of the California Cancer Registry (CCR) (University of Southern California, 2010). The CCR is California's statewide population-based cancer surveillance system that collects information on all cancers diagnosed in California. The CCR falls under the umbrella of the California Department of Public Health’s Cancer Surveillance and Research Branch (CSRB) (University of Southern California, 2010).

Tumor registry data on time between diagnosis and initial surgical treatment for NHW, Hispanic and SEA breast cancer patients was examined to compare differences in this quality of care outcome measure among racial/ethnic groups, as well as between facilities grouped according to their PNP-availability status. NHWs were included in the analysis to serve as a comparison group to the SEA subgroups. Hispanics were also included in the analysis to further illustrate any differences between another ethnic group with an immigrant population and SEAs.

Hispanics may be similar to SEAs in their linguistic and cultural ability to access cancer care services and may be reliant on patient navigators.

"Surgery," as described in the CCR Data Dictionary, is a surgical cancer treatment and is defined as the date the earliest definitive surgery was performed. Median time between diagnosis and initial surgery date, as well as the percent receiving surgery within 30 days after diagnosis were used as the quality of care measures. Literature justifying surgery as a good quality care measure, versus other treatment options (e.g. chemotherapy, radiation therapy, hormone therapy, etc.), is not available. However, surgery is a quality controlled and reliable tumor registry variable, while other treatment options, including chemotherapy, may not always be recorded. Additionally, surgery, as compared to the other cancer treatments, is an in-patient medical procedure and would be available for registry abstracting, which is performed at hospitals. Information on treatments received in the outpatient setting (e.g. chemotherapy and radiation) may not be available to the abstractors.

Outcome measures included: 1) the median time from diagnosis to surgery and 2) percent with surgery within 30 days after diagnosis. These outcome measures were compared for patients in the catchment areas (i.e. census tracts within a 1-mile radius of each facility) of the PNP-available and PNP-unavailable hospitals for SEA, Hispanic, and NHW women. Additional comparisons were made by year of diagnosis, including a 5-year time interval before the NOA legislation (2000-2005) versus afterward (2006-2010).

Because of confidentiality requirements, all statistical analysis requests using cancer registry data were submitted to LA-CSP and conducted in-house. To obtain descriptive statistics of the study population, the first dataset request included frequency distributions and means of demographic variables for the number of female SEA, Hispanic and NHW patients with invasive breast cancer, diagnosed in LA and OC during two time periods. The list of patient demographic variables is detailed in Appendix 3.8-Patient Demographic Variables. To investigate the differences in time between diagnosis and surgery, the second dataset request included frequency distributions by number of months (i.e. <1 month, 1+ months) of the time interval between diagnosis and surgery, and the median time interval between diagnosis and surgery by ethnic group, for the two time periods (2000-2005 and 2006-2010) and by hospitals grouped by their PNP availability status. The list of outcome variables and the process for recoding the calculated variables are detailed in Appendix 3.9-Outcome variables. In order to assess time to treatment at specific health care facilities with or without PNPs, the third dataset request included these measures and grouped the patient data according to their residence distance (in census tracts <1 mile) around each facility.

Initially, the plan was to link the patient data outcome information for patients actually being seen at each facility with their PNP availability status. However this required hospital permission to provide facility specific data. Since very few of the hospitals agreed to give permission, an ecologic approach was used instead, which involved aggregating data for patients residing within a defined radius around each hospital. Geographic data involved the use of facility addresses to produce a list of census tracts (based on data from Census 2000) to determine the catchment area for each facility. The catchment area was originally defined as a 5-mile radius centered at each hospital, but was later reduced to a 2.5-mile radius (see Appendix 3.10) and then a 1-mile radius (see Appendix 3.11) to minimize and avoid overlaps between facilities. A University of Southern California (USC) doctoral student performed statistical analysis of geographic data, with guidance from USC faculty advisors. Census tract data (included one column for the 5-digit county code, one column for the 6-digit county ID, and one column for the combined county and census tract ID) was then matched with patient cases from the LA-CSP to run the statistical analysis on time to surgery by facility PNP availability status.

3.4 – Results

3.4.1 Sample Characteristics

The data presented in Table 3.2-Type of Facility shows the general categorical breakdown of PNP-availability status obtained from the Short Telephone Questionnaire:

Table 3.2 Type of Facility (by availability of PNP)

Type of Facility	TOTAL
PNP-available	4
PNP-unavailable	9
TOTAL	13

Of the 24 health care facilities included in the Facilities List, a total of 14 coordinators or navigators were reached and consented to participate in the Short Telephone Questionnaire to assess the availability of PNPs at their institutions. One health care institution had established a PNP during the Pre-NOA period (with continuing availability through the post NOA period), and this facility was excluded from analysis since it would not have been possible to compare differences in treatment between the two time periods based on availability of the PNP, yielding a sample of 13 facilities. Of the 13, there were four institutions with PNPs developed initially during the Post-NOA period (2006-2010). A total of seven facilities did not develop a PNP between 2000-2010, or afterward. Two facilities that established a PNP during the 2011-2012 period were also categorized as PNP-unavailable, since these hospitals did not develop their program between the NOA five-year period (2006-2010) when data from the cancer registry was available for assessment of time to treatment.

3.4.2 Descriptive of Patient Navigation Programs

In addition to categorizing hospitals, the Short Telephone Questionnaire was used to obtain general information from hospitals with established PNPs. The data in Table 3.3-Short

Telephone Questionnaire Responses presents the basic data given by coordinators, facilitators and navigators from six facilities (four with PNP-available during the study period and two which established a PNP after the study period) with PNPs.

Table 3.3 – Short Telephone Questionnaire Responses

PARiHS Element	**PNP Topics** ***Subgroups***	**A (n=4)**	**UA (n=2)**	**Total (n=6)**
Context	Impetus for establishing program			
	- *Compliance with certification requirements*	*3*	*2*	*5 (83%)*
	- *Other (i.e. Project within facility, grant, ACOS)*	*3*	*2*	*5 (83%)*
	- *Patient Need*	*1*	*1*	*2 (33%)*
	- *Legislation*	*1*	*0*	*1 (17%)*
	NOA related to the establishment of the program = YES	*0*	*0*	*0 (0%)*
	PNP provides cultural & linguistic services to SEAs			
	- *Cambodian: cultural*	*0*	*0*	*0 (0%)*
	- *Cambodian: linguistic*	*0*	*1*	*1 (17%)*
	- *Laotian: cultural*	*0*	*0*	*0 (0%)*
	- *Laotian: linguistic*	*0*	*0*	*0 (0%)*
	- *Thai: cultural*	*0*	*0*	*0 (0%)*
	- *Thai: linguistic*	*0*	*0*	*0 (0%)*
	- *Vietnamese: cultural*	*1*	*0*	*1 (17%)*
	- *Vietnamese: linguistic*	*2*	*0*	*2 (33%)*
Evidence	Stage when navigator matched with patient			
	- *Diagnosis*	*3*	*2*	*5 (82%)*
	- *Treatment*	*2*	*1*	*3 (50%)*
	- *Post-Treatment*	*1*	*1*	*2 (33%)*
	- *Screening*	*1*	*0*	*1 (17%)*
	- *Hospice Care*	*0*	*1*	*1 (17%)*

A=PNP-Available *UA=PNP-Unavailable during study timeframe* *DK=Don't Know*

The response to question #4 of the Short Telephone Questionnaire was primarily used to assess facility awareness of the NOA (Q1) and the legislation's influence on the establishment of PNPs (Q2). When asked, all PNP-available facilities indicated that the NOA *was not* related to the development of their program. The response to this question suggests that current respondents of PNP-available facilities were not aware of the NOA and required additional information about and an explanation of the legislation.

To further assess whether the NOA influenced the development of PNPs (Q2), additional data from the Short Telephone Questionnaire was examined. Survey responses indicated that two of the four PNP-available facilities established PNPs to comply with certification requirements, such as the Commission on Cancer-Cancer Programs Standards 2012 (American College of Surgeons, 2012), and one of the four alluded to institutional program requisites. Patient need and legislation were additional reasons for the development of PNPs. As for the two facilities, which established PNPs after 2010, both indicated certification requirements as a factor for the development of their programs. Patient need and financial support from a funding agency were also cited by these two facilities as contributing factors.

As described earlier, the follow-up mailed Facility Survey was used to gather program specific data about facilities with PNPs and to assess the depth of services provided in relation to the three elements of the PARiHS framework for successful implementation of a program. Of the six facilities with PNPs, five Facility Surveys (three PNP-available during the study time frame and the two which established a PNP after 2010) were completed and returned. Most of the survey's response options allowed respondents to "check all that apply." Therefore, total subgroup responses within each PNP topic does not equal total sample size. The data in Table 3.4-Facility Survey Responses presents the primary responses given by PNPs coordinators, facilitators and navigators.

Table 3.4 - Facility Survey Responses

PARiHS Element	**PNP Topics** ***Subgroups***	**A (n=3)**	**UA (n=2)**	**Total (n=5)**
Context	PNP Target Groups			
	- *All cancer types (breast, colorectal, cervical, lung, prostate)*	*2*	*2*	*4 (80%)*
	- *Uninsured/Underserved, Low-income, Age Group*	*1*	*2*	*3 (60%)*
	- *Ethnic/Language Groups (All, Vietnamese, Hispanic)*	*1*	*2*	*3 (60%)*
	Types of Services Provided			
	- *Education*	*3*	*2*	*5 (100%)*
	- *Scheduling appointments*	*2*	*1*	*4 (80%)*
	- *Access to treatments or post-treatments*	*1*	*2*	*3 (60%)*
	- *Counseling*	*2*	*1*	*3 (60%)*
	- *Pain Management*	*1*	*2*	*3 (60%)*
	Stage when Patients Managed Through System			
	- *Diagnosis to treatment*	*3*	*2*	*5 (100%)*
	- *Screening to diagnosis*	*3*	*1*	*4 (80%)*

	- *Treatment to follow-up*	*3*	*1*	*4 (80%)*
	Level of Support Provided by Navigators - *Visits only upon request* - *Doctoral referral, patient call, inpatient/outpatient visit*	 *2* *2*	 *2* *0*	 *4 (80%)* *2 (40%)*
	Who Contributed to Development of PNP - *Facility Staff* - *Administration* - *Guidelines/Accreditation Requirements*	 *2* *1* *2*	 *2* *2* *0*	 *4 (80%)* *3 (60%)* *2 (40%)*
	Funding Received=YES - *Foundation* - *Donations* - *Other (not specified)*	1 *0* *1* *0*	2 *1* *0* *1*	3 (60%) *1 (20%)* *1 (20%)* *1 (20%)*
	Mechanisms for Additional Services =YES - *Referrals*	3 *3*	2 *1*	5 (100%) *4 (80%)*
Facilitation	How Leaders Assisted with Development of PNP - *Development of ideas/program* - *Obtain funding* - *Obtain facility approval* - *Recruitment* - *Marketing*	 *3* *2* *2* *1* *2*	 *2* *2* *2* *1* *0*	 *5 (100%)* *4 (80%)* *4 (80%)* *2 (40%)* *2 (40%)*
	Type of Resources Used in Program Development - *Guideline review, other (not specified)* - *Community meetings* - *Flyers* - *Training Curriculum*	 *2* *0* *1* *0*	 *0* *1* *0* *1*	 *2 (40%)* *1 (20%)* *1 (20%)* *1 (20%)*
	Type of Patient Navigators - *Nurse navigators* - *Social workers* - *Patient advocates* - *Lay Health Workers*	 *2* *1* *1* *1*	 *1* *1* *0* *0*	 *3 (60%)* *2 (40%)* *1 (20%)* *1 (20%)*
	Paid Navigators = YES How navigators are paid - *Hospital/health care facility*	3 *3*	2 *1*	5 (100%) *4 (80%)*
	Trained Patient Navigators = YES - *Training through certification, seminars*	2 *2*	1 *0*	3 (60%) *2 (40%)*
	Requirements to be Patient Navigator - *Oncology Certified Nurse/Nurse Practitioner* - *Bachelor degree* - *Nurse license*	 *1* *1* *1*	 *1* *1* *0*	 *2 (40%)* *2 (40%)* *1 (20%)*
	Barriers - *Lack of financial resources* - *Insufficient staff*	 *1* *1*	 *2* *1*	 *3 (60%)* *2 (40%)*
Evidence	# of Full-Time Equivalent (FTE) Patient Navigators - *1* - *2* - *3* - *4* - *5+*	 *1* *0* *0* *0* *1*	 *1* *1* *0* *0* *0*	 *2 (40%)* *1 (20%)* *0 (0%)* *0 (0%)* *1 (20%)*
	# of Patients Participated in PNP - *Received services* - *Breast cancer patients* - *SEA*	 *100-230* *~100* *~10%*	 *580* *DK* *DK*	 *100-580* *DK* *DK*

	How Navigators Matched with Patients			
	- *Cancer type*	*3*	*2*	*5 (100%)*
	- *Language*	*0*	*1*	*1 (20%)*
	- *Geographic area*	*0*	*1*	*1 (20%)*
	Mechanisms to Assess Timely Receipt of Care = YES	3	1	4 (80%)
	- *Charts*	*3*	*1*	*4 (80%)*
	- *Survey*	*2*	*1*	*3 (60%)*

A=PNP-Available *UA=PNP-Unavailable during study timeframe* *DK = Don't Know*

Data from the Facility Survey was used to determine if other factors, aside from the NOA, contributed to the development of PNPs (Q2). Survey responses indicate that facility staff (2/3 PNP-available and 2/2 PNP-unavailable facilities) and hospital administration (1/3 PNP-available and 2/2 PNP-unavailable facilities) were instrumental in establishing a PNP. Data also shows that these program leaders contributed by developing ideas for the PNP (3/3 PNP-available and 2/2 PNP-unavailable), obtaining funds (2/3 PNP-available and 2/2 PNP-unavailable), and securing facility/administrative approval (3/3 PNP-available and 2/2 PNP-unavailable). Some of these leaders facilitated the process through community meetings (1/2 PNP-unavailable), posting flyers (1/3 PNP-available) and by creating a training curriculum (1/2 PNP-unavailable).

With regards to funding, one PNP-available hospital received financial assistance through donations while the other two PNP-available facilities did not have any form of funding. Both PNP-unavailable institutions received financial support in the form of a grant and/or hospital operational funds. Another factor that might have contributed to the development of PNPs was the type of patient navigator available at these health care institutions. Most were primarily nurse navigators (2/3 PNP-available and 1/2 PNP-unavailable) and social workers (1/3 PNP-available and 1/2 PNP-unavailable), while some of the PNP-available facilities identified lay health workers and patient advocates as patient navigators.

In terms of barriers to the development of PNPs, one PNP-available and both PNP-unavailable facilities indicated funding and staffing as obstacles. The PNP-available facility elaborated by stating their need for dedicated personnel to assist with organizing their PNP.

To assess the availability and quality of PNP at facilities with established PNPs (Q3), data gathered from the Facility Survey show that cancer care services for SEAs was minimal. According to data from the Short Telephone Questionnaire, a total of three out of four PNP-available facilities stated that most patients were introduced to navigators at the diagnosis stage of the cancer continuum, followed by treatment and post-treatment stages.

As for culturally specific patient navigation services for SEA patients, looking back at data from the Short Telephone Questionnaire, two of the four PNP-available facilities stated that additional information about cultural or linguistic resources for SEA patients is currently available at their institution. Both hospitals provided Vietnamese language services, one of which incorporated some form of cultural services but did not elaborate on the specifics. None of the other SEA cultural or linguistic services were offered at the identified facilities.

Background information about the PNPs at PNP-available and PNP-unavailable facilities indicate that services are available to patients of all income levels and provided to all cancer patients, regardless of the type of cancer. Only one PNP-available and two PNP-unavailable facilities noted ethnic specific target groups, of which the PNP-available facility expressly focused on Vietnamese patients. The primary service offered by all of the hospitals was education, while scheduling appointments and counseling served as secondary services rendered by two out of three PNP-available facilities. In contrast, access to treatments/post-treatments and pain management were identified as secondary services by the two PNP-unavailable facilities. Although the majority of the facilities indicated that their programs navigated patients at each phase of the cancer continuum (i.e. from screening to follow-up), all three of the PNP-available and two of the PNP-unavailable hospitals provided navigation services between diagnosis and treatment. Most facilities (2/3 PNP-available and 2/2 PNP-unavailable) noted that PN services were granted upon request and mechanisms were in place for referring patients to additional resources. Data on the frequency of requests for patient navigation services, as well as detailed information about referral mechanisms was not assessed through the Facility Survey.

To further investigate the quality of PNPs, data on how PNPs were established at hospitals was examined. Responses to facilitation-specific questions showed that leaders (i.e. facility staff and administration) at both PNP-available and PNP-unavailable hospitals primarily contributed to the development of program ideas, followed by the acquisition of funding (i.e. through foundations and donations) to support patient navigation services, and obtaining facility approval to create PNPs. All five hospitals with PNPs indicated that their patient navigators, mainly nurse navigators and social workers, were paid through funding from the hospital and already served as Oncology Certified Nurses or Nurse Practitioners. Other requirements to be a patient navigator included a bachelor degree or a nursing license. A total of three facilities (two PNP-available and one PNP-unavailable) provided trainings, but the process was not clearly outlined (i.e. training through certification program or seminars). Only one PNP-available facility employed 5+ full-time equivalent (FTE) patient navigators while others had <3 FTE navigators (one PNP-available and two PNP-unavailable). Although each hospital did not specify the number of SEA breast cancer patients assisted through their PNPs, the total number of patients who received navigation services was over 200 in 2011 for all PNP-available facilities, and nearly 600 in 2011 for all PNP-unavailable facilities. Charts (n=4) and surveys (n=3) were used at hospitals with PNPs to assess whether or not patients received cancer care services in a timely manner. The Facility Survey did not assess background information about chart extraction and the administration of surveys.

3.4.3 Patient Demographics

Data requested from the LA-CSP included date of diagnosis and date of initial surgery for NHW, Hispanic and SEA women residing in LA and OC, and diagnosed with invasive breast cancer within two time periods: P1= pre-NOA (2000-2005) and P2= post-NOA (2006-2010). Patient data on women diagnosed with in situ breast cancer was not included. Due to the low number of Cambodian, Laotian and Thai breast cancer patients, these three SEA subgroups were combined as one and identified in the data as “LCT” (see Table 3.5).

Table 3.5 – Total number of female invasive breast cancer cases by race/ethnicity in LA & OC, 2000-2010

	Pre-NOA 2000-2005	Post-NOA 2006-2010	TOTAL
NHW	27,291	21,567	48,858
Hispanic	7,956	7,820	15,776
Vietnamese	433	526	959
LCT*	151	128	279
TOTAL	**35,831**	**30,041**	**65,872**

**Laotian, Cambodian, Thai*

General demographic data (see Table 3.6-Tumor Registry Characteristics) show that the largest proportion of SEA women were diagnosed with breast cancer at 50-64 years of age (P1=39.95% for Vietnamese and 47.68% for LCT, and P2=39.92% for Vietnamese and 56.25% for LCT), whereas the largest proportion of NHWs were diagnosed at age 65+ (P1=46.76% and P2=45.72%). Over 58% of all SEAs, 55% of Hispanics, and 54% of NHWs were married. Less than 3% of any group was not insured and most had either public or private insurance during the two time periods. Socioeconomic (SES) status, based on census tract measures of education and income at the block group level (State of California, 2010), indicate more than a third (39% at P1 and P2) of all NHWs resided in the high-SES quintile, while the largest proportion of

Vietnamese women were identified to fall within the low-medium SES quintile for both time periods (P1=31%, P2=35%), and similarly for LCT women (P1=22%, P2=28%). However, Hispanics had the largest proportion of cases residing in the lowest SES quintile (P1=35%, P2=34%).

Table 3.6 – Tumor Registry Characteristics
(Percent of female invasive breast cancer cases, by race/ethnicity, by selected characteristics, in LA & OC, over two time periods)

	P1	P2	P1	P2	P1	P2	P1	P2	P1	P2
Age at Diagnosis	**25-34**		**35-49**		**50-64**		**65+**			
NHW	1.35	1.08	17.30	17.03	34.59	36.18	46.76	45.72		
Hispanic	4.19	3.80	32.10	29.42	35.13	37.76	28.58	29.02		
Vietnamese	2.77	4.37	39.03	34.03	39.95	39.92	18.24	21.67		
*LCT**	2.65	3.13	33.77	21.09	47.68	56.25	15.89	19.53		
Marital Status	**Single, never married**		**Married**		**Separated**		**Divorced**		**Widowed**	
NHW	13.39	15.08	54.50	54.70	1.11	1.01	11.50	12.03	19.50	17.18
Hispanic	19.57	21.70	57.01	55.32	2.00	1.92	8.70	9.59	12.72	11.48
Vietnamese	19.09	22.02	63.72	69.09	0.72	0.40	7.88	3.03	8.59	5.45
*LCT**	17.93	21.14	63.45	58.54	0.69	0.81	8.97	8.13	8.97	11.38
SES	**Low**		**Low-Medium**		**Medium**		**Medium-High**		**High**	
NHW	5.05	5.94	11.41	10.82	18.03	16.95	26.14	26.36	39.37	39.92
Hispanic	35.17	34.37	25.68	25.31	17.66	17.69	12.56	12.81	8.94	9.82
Vietnamese	15.70	13.50	31.18	34.98	21.71	23.38	15.01	13.12	16.40	15.02
*LCT**	20.53	22.66	22.52	28.13	21.19	17.19	19.87	16.41	15.89	15.63
Insurance	**Private**		**Public**		**Not Insured**					
NHW	61.76	59.25	37.31	39.84	0.92	0.91				
Hispanic	54.78	49.56	42.07	48.17	3.16	2.27				
Vietnamese	57.48	51.05	40.68	47.78	1.84	1.17				
*LCT**	53.62	45.08	42.03	52.46	4.35	2.46				

P1 = Time period 1, pre-NOA (2000-2005) *P2 = Time period 2, post-NOA (2006-2010)*
Note: Each race/ethnic group line, within each time period = 100%
**Laotian, Cambodian, Thai*

In terms of Stage at Diagnosis, data was defined as: 1) localized or Stage I, breast cancer confined to the primary tumor site-has not spread to lymph nodes or distant sites, 2) regional or Stages II/III, tumor has spread to regional lymph nodes, and 3) distant or Stage IV, tumor has metastasized-spread to distant tissues or organs (National Cancer Institute, 2013).

Table 3.7 – Tumor Registry: Stage at Diagnosis
(Percent of female invasive breast cancer cases, by race/ethnicity, by stage at diagnosis, in LA & OC, over two time periods)

	Localized		Regional		Distant	
	P1	P2	P1	P2	P1	P2
NHW	62.5	64.1	31.0	29.5	4.2	4.7
Hispanic	53.3	54.5	38.8	37.7	5.3	5.9
Vietnamese	61.2	64.5	34.0	30.4	3.0	3.6
*LCT**	57.6	57.8	31.8	30.5	7.3	9.4

P1 = Time period 1, pre-NOA (2000-2005) *P2 = Time period 2, post-NOA (2006-2010)*
**Laotian, Cambodian, Thai*
Notes: a)"Unstageable "was excluded from the table, b) Each race/ethnic group line, within each time period <100%

Results show that all ethnic groups generally followed the same pattern between the two time periods for each stage, such that there was a small increase from P1 to P2 in the percentage of women diagnosed with localized (1.2-3.3% increase) and distant (0.5-2.1% increase) breast cancer, while the distribution of cases at the regional stage shows a decline (between 1.1-4.6% decline) from P1 to P2 (see Table 3.7, Chart 3.1 and Chart 3.2). In terms of differences between ethnic groups, the proportion of SEAs with localized (Vietnamese P1=61.2% and P2= 64.5%; LCT P1=57.6% and P2=57.8%) disease was more similar to NHWs (P1=62.5% and P2=64.1%) than Hispanics (P1=53.3% and P2=54.5%), who had higher proportions with regional disease. However, LCT's had the highest proportion with distant disease compared to the other racial/ethnic groups (P1=7.3%, P2=9.4%) (see Chart 3.1 and 3.2).

Chart 3.1 – Period 1, All Ages by Stage at Diagnosis
(Percent of female invasive breast cancer cases in LA & OC, 2000-2005)

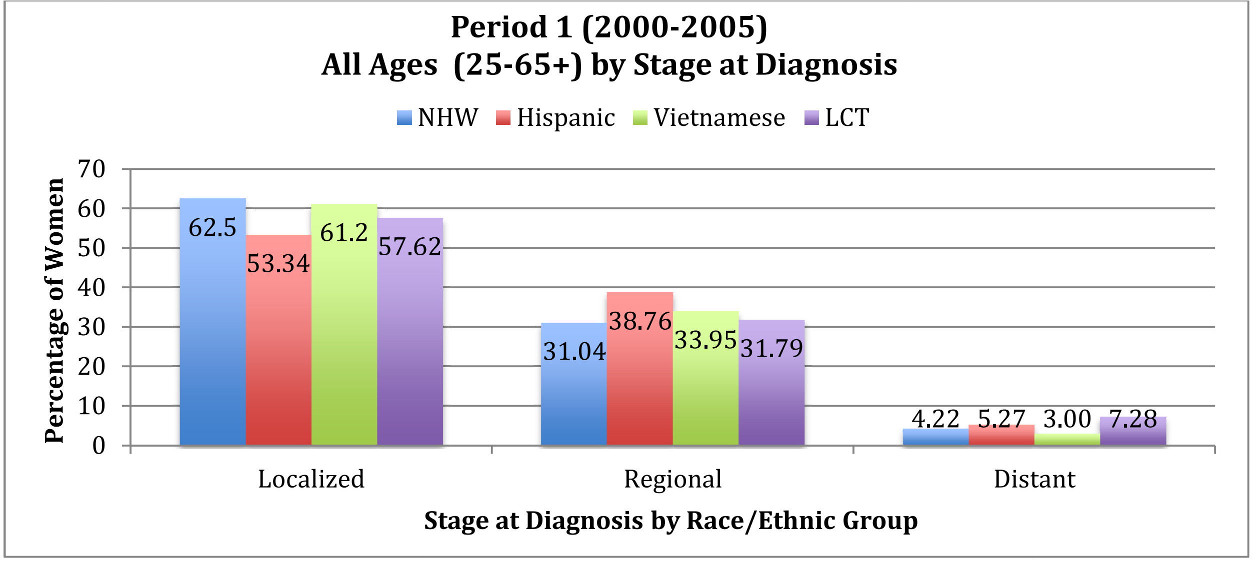
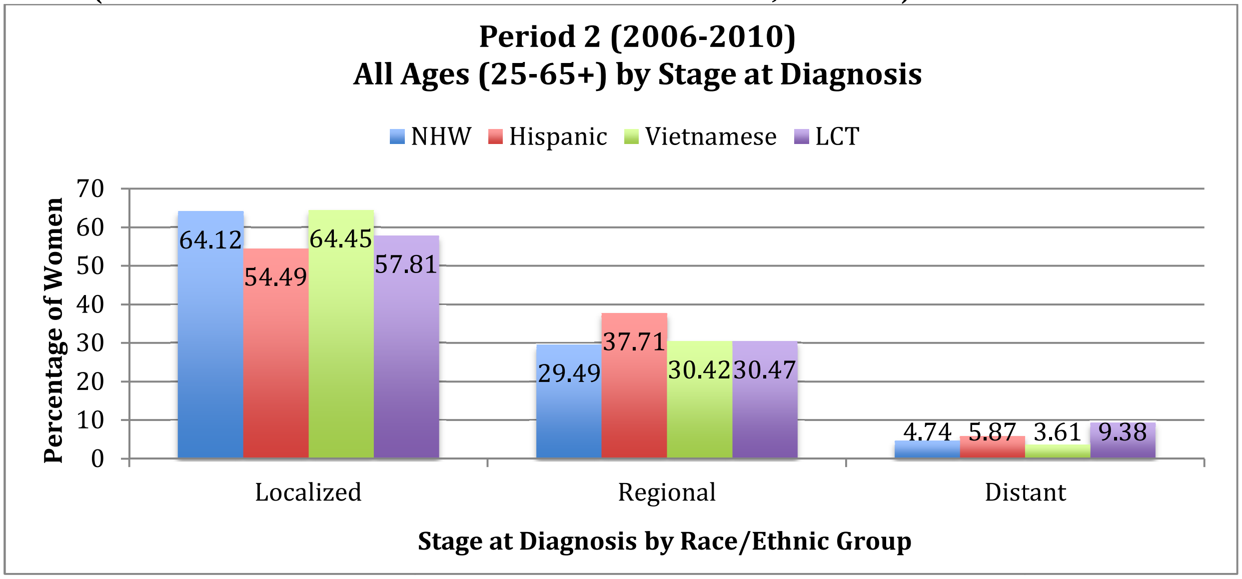


Chart 3.2 – Period 2, All Ages by Stage at Diagnosis
(Percent of female invasive breast cancer cases in LA & OC, 2006-2010)



3.4.4 Quality of Care & Health Care Utilization

As previously described, since facility permission to examine data on patients being seen at each facility was not obtained, an ecological analysis was conducted by examining outcome measures of the patients living in the census tracts surrounding each facility. Institutional addresses were used to define the focal point for the catchment areas. The catchment areas were first constructed by defining a 2.5-mile radius around each facility, but due to the close proximity of some of the facilities, there was substantial overlap of these catchment areas (see Appendix 3.10-Map of 2.5-mile Catchment Area). Thus the catchment areas were reduced in size to a 1-mile radius to minimize overlap between facilities (see Appendix 3.11-Map of 1-mile Catchment Area). By reducing the size of the catchment area the number of breast cancer patient cases also decreased (see Table 3.8-Breast Cancer Cases in Study Catchment Areas).

Table 3.8-Breast Cancer Cases in Study Catchment Areas
(Total number of female invasive breast cancer cases, by hospitals in LA & OC, by PNP facility type, in catchment areas)

	2.5-mile radius		1-mile radius	
Hospital ID	**PNP-available (n=4)**	**PNP-unavailable (n=9)**	**PNP-available (n=4)**	**PNP-unavailable (n=9)**
1		1,010		279
2		1,483		488
3		926		255
4		1,159		372
5	674		196	
6		868		174
7		894		235
8		1,259		383
9	1,469		663	
10		1,276		244
11	1,505		393	
12		1,171		281
13	994		366	
TOTAL	**4,642**	**10,046**	**1,618**	**2,711**

Dates data accessed: 2.5-mile radius (5/31/2013), 1-mile radius (6/24/2013)
PNP = Patient Navigation Program

Using data based on the 1-mile catchment area, the total number of women identified as having received surgery within 30 days (<30 days) after diagnosis show that the amount of SEA breast cancer patient cases is less than 300 for both time periods compared to NHWs and Hispanics (see Table 3.9- Received Surgery Within 30 days, By Time Period). To assess whether enactment of the NOA and the availability of PNPs was instrumental in improving the time between diagnosis and surgery (Q4), aggregated patient data among PNP-available and PNP-unavailable facilities were compared. The proportion of patients, at all stages, who received surgery within 30 days (see Table 3.9) was higher at pre-NOA period at both PNP-available and PNP-unavailable facilities. Compared to Hispanics and NHWs, the number of SEAs who received surgery within 30 days was higher at both time periods in PNP-available facilities, although the numbers are small.

Table 3.9 – Received Surgery within 30 days (<30 days), by time period
(Number & Percent of female invasive breast cancer cases in study catchment areas)

	PNP - Available		**PNP-Unavailable**	
ALL STAGES	Pre-NOA N (%)	Post-NOA N (%)	Pre-NOA N (%)	Post-NOA N (%)
NHW	433/703 (61.6%)	290/635 (45.7%)	482/783 (61.6%)	267/593 (45.0%)
Hispanic	70/104 (67.3%)	53/112 (47.3%)	296/561 (52.8%)	190/482 (39.4%)
Vietnamese	10/14 (71.4%)	7/14 (50.0%)	68/85 (80.0%)	47/106 (44.3%)
LCT	2/2 (100.0%)	0/0 (0.0%)	12/22 (54.5%)	8/12 (66.7%)
Total	**515/823 (62.6%)**	**350/761 (46.0%)**	**858/1451 (59.1%)**	**512/1193 (42.9%)**

Pre-NOA = 2000-2005 Post-NOA = 2006-2010 PNP = Patient Navigation Program

With regards to the number of days between diagnosis and surgical treatment for “all stages”, the median time to surgery after diagnosis was substantially longer in the post-NOA period compared to the pre-NOA period, however these trends were similar for patients at PNP-available and PNP-unavailable facilities during the two time periods (see Table 3.10). Looking specifically at SEAs for “all stages”, data shows that median time to surgery was generally higher for Vietnamese women during the post-NOA period at both facility types compared to LCTs (however the numbers for LCT were small). Nevertheless, the medians for the Vietnamese were very similar to those for NHWs.

Table 3.10 – Median time (days) to Surgery, by stage of diagnosis
(Female invasive breast cancer cases in study catchment areas)

	PNP-Available		PNP-Unavailable	
ALL STAGES	Pre-NOA Days (N)	Post-NOA Days (N)	Pre-NOA Days (N)	Post-NOA Days (N)
NHW	22 (671)	30 (592)	21 (729)	30 (537)
Hispanic	18 (97)	32 (102)	26 (522)	35 (421)
Vietnamese	7 (14)	29 (13)	10 (84)	29 (92)
LCT	8 (2)	0 (0)	13 (17)	12 (11)
Total	**22 (784)**	**30 (707)**	**21 (1352)**	**31 (1061)**

Pre-NOA = 2000-2005 *Post-NOA = 2006-2010* *PNP = Patient Navigation Program*

3.5 – Discussion

The literature shows that patient navigation is now increasingly seen as a vital component in transforming health systems to focus on patient-centered health care. This study addressed the gaps in the literature by investigating whether the enactment of the NOA signaled an institutional recognition of the contribution of PNPs as a viable service to improve access to cancer care services and quality of care for SEA breast cancer patients. More specifically, the research 1) assessed health care facility awareness of the NOA, 2) explored the NOA’s role in establishing PNPs, 3) investigated the quality of the PNPs in terms of the cancer care services provided for SEAs, and 4) examined whether the NOA had an impact on time to treatment.

3.5.1 Awareness of the NOA

Detailed information about the NOA indicates that the policy was authorized to appropriate funds to eligible applicants beginning 2006 and not beyond the end of September 2010, hence the designation of the post-NOA (2006-2010) funding period (U.S. Government Printing Office, 2005). Eligible NOA grant applicants include health care institutions (i.e. public or nonprofit private health centers, a health facility rural health clinics, or academic health center, etc.) who can demonstrate that funds will be utilized for the expansion or development of new services to individuals who would otherwise not have access to health care services (U.S. Government Printing Office, 2005). Therefore, any health care institution with the intent to develop a PNP was eligible to apply for NOA funds. However, additional information pertaining to the selection criteria for the receipt of funds is not available and specific information about funded institutions is limited.

The findings suggest there was no association between the NOA and the availability of PNPs in the LA and OC areas of the study after 2005. Based on responses to the Short Telephone Questionnaire, only four PNPs were developed and implemented by PNP-available facilities during the 5-year post-NOA period and questionnaire respondents at these hospitals were not familiar with the NOA. Another two PNPs were created by PNP-unavailable facilities after the NOA funding period ended in 2010, and these institutions were also not aware of the NOA. Due to the format of the telephone survey, knowledge and awareness of the NOA was only asked of facility representatives at hospitals with established PNPs. If respondents indicated "no" to the availability of a PNP, the survey ended. Thus, the data collected does not provide information to determine if facility representatives, from facilities without PNPs, were familiar with the NOA.

Additionally, participants contacted and identified for the Short Telephone Questionnaire may not have been the most appropriate individuals to respond to the survey and not all questionnaire respondents may have been in positions of authority to be familiar with or contribute to decisions associated with federal policies. Lack of NOA awareness among facilities with PNPs may also be due to the terminology used to identify programs designed for cancer patients. Not all cancer care services are labeled or identified as "patient navigation", so connecting to the appropriate department or identifying a knowledgeable representative to gather data about their cancer care programs may not have been made.

3.5.2 NOA Role in PNP Development

Investigation of the NOA's role in establishing PNPs, as noted from the Short Telephone Questionnaire, indicates that PNP-available facilities did not develop programs because of the legislation. This finding correlates with the initial policy analysis, which indicated that the NOA funded four sites in California but did not allocate funding to any of the identified PNPs in LA or OC. However, the policy may have contributed to the increased availability of PNPs such that the federal recognition and support of PNPs may have served as affirmation and as a catalyst for revisions to institutional policy or practice guidelines to establish patient-centered care programs for cancer patients, which may have been "fulfilled" in other ways. For instance, the Commission on Cancer-Cancer Programs Standards 2012 by the American College of Surgeons was identified as the reason behind the development of PNPs at two PNP-available facilities. While the two PNP-unavailable hospitals indicated certification requirements was one of the driving factors for the establishment of PNPs. The results from the Short Telephone Questionnaire also imply that policies, whether at the federal or institutional level (i.e. adherence to guidelines from the Commission on Cancer), exert some influence in guiding facilities to evaluate the feasibility of establishing patient-centered programs.

Although specific certification or accreditation programs were not identified by the two PNP-unavailable facility representatives, nor was this topic assessed further by the surveys, an assumption may be that certification requirements for the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS Standards) could have prompted the development of PNPs. For instance, the National CLAS Standards (a total of 15 standards) was formally adopted in 2001 by the Office of Minority Health, a division of the Department of Health and Human Services, and was designed to assist individuals and health care organizations to help eliminate health care disparities by tailoring health care services to meet an individual's cultural and linguistic preferences (Cross Cultural Health Care Program, 2014). The patient-centered communication standards (CLAS Standards #4 to #7) was approved by The Joint Commission-Board of Commissioners in December 2009 and took effect in January 2012 (Cross Cultural Health Care Program, 2014; Office of Minority Health, 2013; The Joint Commission, 2011). The patient-centered communication standards state that facilities seeking accreditation through The Joint Commission and institutions receiving federal funds must meet standards associated with 1) educating and training leaders, 2) offering individuals language assistance, 3) informing individuals about the availability of language services, and 4) ensuring the competence of leaders providing language assistance (Office of Minority Health, 2013). Thus, health care institutions may decide that development of PNPs is an ideal vehicle for addressing this certification requirement while simultaneously providing access to and assistance with other health care services.

Descriptive information gathered from the Facility Survey point to the diversity and the complexity of services offered by existing PNPs, indicating that standardized guidelines for the development of navigation services have not been established. However, with the reauthorization of the NOA through 2015, the policy now requires new grantees to ensure that patient navigators meet core proficiencies and that organizations verify the navigators' expertise according to the work they will perform (George Washington Cancer Institute, 2013; Moy & Chabner, 2011). Additionally, Standard 3.1-“Patient Navigation Process” of the Commission on Cancer outlines the four criteria for establishing PNPs in order for an institution to be deemed compliant and receive accreditation (American College of Surgeons, 2012). Therefore, minor steps are being made towards establishing standardized guidelines. Although both entities provide parameters for the development of PNPs, compliance are only required of facilities seeking accreditation or to maintain/access federal funds. These guidelines are not applicable to organizations and smaller health care facilities that develop PNPs based on patient requests or community needs.

Responses from the survey also indicate that program support from facility staff and hospital administration, in the form of program development, securing facility and administrative approval, and obtaining funds, were primary factors in the development of PNPs. Therefore, policies and guidelines may not prove meaningful unless program leaders are present and take necessary actions to support initiatives, or until reimbursement becomes part of the capitation package with more evidence to encourage the change.

The type and availability of patient navigators might have also been contributing factors in the development of PNPs. Since nurses and social workers served as patient navigators for the PNPs at PNP-available and PNP-unavailable institutions, there may have been less concern from hospital administration and program supporters about the patient navigators' knowledge of the health care system and their ability to provide care for breast cancer patients. As a result of their clinical background, these individuals require less training than lay health workers and they may already have the skills and credentials to support and guide breast cancer patients throughout the cancer care continuum. Additionally, recent studies of patient navigation programs found nurse navigators to be valuable resources in enhancing the patient's cancer experience by providing education and information during early cancer care, improving outcomes (e.g. length of hospital stay), and reducing problems with care coordination (Korber, Padula, Gray, & Powell, 2011; Lee et al., 2011; Wagner et al., 2013).

Conversely, financial assistance and insufficient staffing were highlighted by three out of five program facilitators/navigators as barriers to the development of PNPs, suggesting the need to address issues associated with capacity building and program sustainability. Without proper personnel to conduct the day-to-day organization and management of the PNPs and to maintain program activities, as well as funding to support patient navigators and program staff, PNPs will cease to exist.

3.5.3 Availability & Quality of PNPs

Most notably, data collected from the Short Telephone Questionnaire on the quality of PNPs and the availability of cancer care services provided to SEAs show that such services were limited at facilities with PNPs. A total of two out of four PNP-available facilities indicated that linguistic and cultural services were available to patients, but only one hospital stated that their program specifically targeted Vietnamese patients by providing Vietnamese interpreters. According to statistics from the LA-CSP, this OC-based facility provides assistance to 4.3% of SEAs, while the other two PNP-available facilities serves approximately 2-3% of the SEA community residing in LA. Of the two facilities with PNPs after 2010, one provides assistance to 6% of SEAs while the other serves no more than 2-3%. Although the proportion of SEAs at these facilities is low, the availability of linguistic services for Cambodians, a group previously noted as having the highest rate (10.6%) of limited English proficiency (LEP) in comparison to other AA groups, was lacking in the contacted facilities (Wilson, Chen, Grumbach, Wang, & Fernandez, 2005). The limited resources available to SEAs may also be attributed to the lack of linguistically and culturally trained and qualified individuals for these AA subgroups. Although the PNP-available facility, which offers Vietnamese language assistance, is geographically located near a Vietnamese enclave, one cannot assume that all Vietnamese patients will access cancer care services at that hospital.

To further assess the availability and quality of PNPs, a review of the Facility Survey data supports the fact that services for SEAs is lacking, such that only one of the PNP-available facilities specifically targeted patients from a SEA community. Data also shows that the second PNP-available hospital focuses on uninsured or underserved and low-income individuals, while the third did not specify. Conversely, both facilities that developed PNPs after 2010 provided services to uninsured/underserved, low-income, all age groups and all ethnic groups. Additionally, assistance is available to individuals of all cancer types. These findings indicate that available PNPs are not selective and are open to patients with the greatest needs. Yet, of the four hospitals with PNPs identified, only one had services tailored for Vietnamese patients. Given the proportion of SEA patients served at these facilities, the availability of PNPs targeting this AA subgroup appears to be enough at this point in time. There also appears to be a limited demand for PNPs or resources for SEAs. However, these are only assumptions and additional research is warranted to fully ascertain the level of cultural and linguistic services needed and requested by SEAs receiving care at these facilities.

With regard to the quality of PNPs, a review of the type of assistance provided shows that education was the primary service offered by the PNPs at all facilities (PNP-available and PNP-unavailable), followed by functional tasks (i.e. scheduling appointments and access to treatments). The data suggests that knowledge about cancer and disease management, specifically breast cancer, would serve as the greatest advantage of PNPs, especially for ethnic groups with linguistic barriers and limited knowledge of the U.S. health care system. According to the Facility Survey, patients are matched with navigators based on their cancer type and assistance is provided only upon request, as indicated by two PNP-available and two facilities with PNPs established after 2010. Results also show that patient navigators at PNP-available and the hospitals with PNPs established after 2010 provide assistance at each stage of the cancer continuum, but primarily during the period between diagnosis and treatment. This suggests that institutions recognize the importance of access to cancer care services and getting patients to timely treatments. Factors associated with timely receipt of treatment may be due to the 1) diversity and complexity of current breast cancer treatments, 2) severity of a patient’s cancer diagnosis, or 3) patient's comfort level and capacity to access the health care system. For SEAs, especially new immigrants, time to treatment issues may be linked to their limited knowledge on how to access cancer care services, which may also be influenced by language and cultural practices.

The availability and quality of PNPs can also be measured by the patient navigators' background. Findings from the Facility Survey indicate that requirements to serve as a navigator has not been standardized such that two hospitals (a PNP-available and a PNP-after 2010) stated that navigators should have at least have a bachelor's degree, some (a PNP-available and a PNP-after 2010) noted that their navigators should be Oncology Certified Nurses or Nurse Practitioners, while others (two PNP-available) did not have established job descriptions and simply identified navigators according to their level of experience. The data suggests that familiarity with cancer care services is important, yet the skills and understanding to work with ethnic specific populations has not been identified as criteria for PNPs.

3.5.4 Time to Treatment

Secondary analysis of tumor registry data was conducted to explore health care utilization among SEA women, focusing specifically on timely receipt to treatment (i.e. surgery within 30 days) after diagnosis. However, quantitative analyses did not yield enough information for SEAs because of small sample sizes. The low number of patient cases is attributed to the geographic proxy approach conducted in lieu of hospital permissions to review facility specific patient cases. An initial review of the data, comparing PNP-available and PNP-unavailable facilities, suggests that the overall percentage of women for "all stages" who received surgery within 30 days after diagnosis during the two time periods did not differ by availability of PNPs, but both groups showed a reduction in the proportion getting surgery within 30 days between the Pre-NOA and Post-NOA time periods (Pre-NOA: PNP-available =62.6%, PNP-unavailable

=59.1% and Post-NOA: PNP-available =46.0%, PNP-unavailable =42.9%). These results did not show that SEAs differed from NHWs on these outcome measures, although the numbers of SEAs were small.

The few number of SEA patient cases at both PNP-available and PNP-unavailable facilities would suggest that this population group may have either 1) sought surgical care at hospitals other than those identified for the study, 2) declined to seek breast cancer treatment, or 3) chose different treatment approaches. Additional research is needed to fully ascertain the reason for the low number of SEA patient cases. Results also indicate that SEAs followed the general trend of the benchmark group (NHWs) and Hispanics, such that median time to surgery for "all stages" was better pre-NOA at PNP-available than PNP-unavailable facilities. These findings suggest that the availability of patient navigators, as implemented in these institutions, was not associated with improved time to treatment for SEA women. However, this study did not assess whether patients, at the identified facilities, actually utilized the patient navigation services. Further research is needed to fully assess utilization of services offered by PNPs.

Additionally, the higher median time to surgery post-NOA may be attributed to the increased variety and complexity of breast cancer treatment options, such as the availability of neoadjuvant therapy, which may cause women to delay surgery (Chong et al., 2010). A review of current approaches to breast cancer treatment indicates that the benefits of neoadjuvant treatment involve increased likelihood of breast conservation and broader surgical options (Connolly & Stearns, 2013). However, a recent study among AA women in California who were diagnosed with early stage breast cancer suggests that AA women do not follow this trend and tend not to choose breast-conserving surgery (Gomez et al., 2012). The research by Gomez and colleagues may be indicative of the low number of SEAs, compared to NHW and Hispanics, who received surgery within 30 days for this dissertation study.

Overall, the results presented in this research illustrates that the NOA did not directly contribute to the availability of PNPs and there is no support that the NOA improved the quality of care measures assessed in this study.

3.6 – Limitations

A larger sample of facilities with PNPs and analysis of time to treatment for patients actually using the PNP versus those not using a PNP may provide a better assessment of the association between PNPs and quality of care measures, and would allow for control of other confounding factors that may impact treatment delay. Patient reported measures, such as satisfaction with care, should also be considered in future evaluations of PNPs.

3.7 – Appendices

Appendix 3.1 - Facilities List

Location	Hospitals where SEA Patients were seen	Percent Of SEA Patients seen	Address
LA	Garfield Medical Center	15%	525 N. Garfield Ave., Monterey Park, CA 91754
LA	Hollywood Presbyterian/ Queen of Angels	6%	1300 North Vermont Avenue, Los Angeles, CA 90027
LA	Huntington Memorial	6%	100 W. California Blvd., Pasadena, CA. 91105
LA	LAC/USC	6%	1200 North State Street, Los Angeles, CA 90033
LA	Alhambra Community/ Alhambra Hospital Medical Center	approx. 2-3%	100 South Raymond Avenue, Alhambra, CA 91801
LA	City of Hope	approx. 2-3%	1500 East Duarte Road, Duarte, CA 91010
LA	Fountain Valley Community/ Fountain Valley Regional Hospital-The Center for Breast Care	approx. 2-3%	11190 Warner Avenue, Suite 214, Fountain Valley
LA	Kaiser Baldwin Park	approx. 2-3%	1011 Baldwin Park Boulevard, Baldwin Park, CA 91706
LA	Kaiser LA	approx. 2-3%	4867 Sunset Boulevard, Los Angeles, CA 90027
LA	Kaiser Panorama	approx. 2-3%	13651 Willard Street, Panorama City, CA 91402, Health Education = Central Medical Office Bldg., 13652 Cantara St, North 2 Medical Offices
LA	Kaiser Woodland Hills	approx. 2-3%	5601 De Soto Ave. Woodland Hills, CA 91365 & Complete Care Mgmt = Medical Office Tower, Entrance 5, 3rd Floor
LA	Long Beach Memorial	approx. 2-3%	2801 Atlantic Avenue, Long Beach, CA 90806
LA	Northridge Medical Center	approx. 2-3%	18300 Roscoe Boulevard, Northridge, CA 91325
LA	San Gabriel Community/ San Gabriel Valley Medical Center	approx. 2-3%	438 W Las Tunas Dr, San Gabriel, CA 91776 626-289-5454
LA	Glendale Adventist Medical Center	Not available	1509 Wilson Terrace, Glendale, CA 91206
LA	Providence St. Joseph Medical Center - Disney Family Cancer Center	Not available	181 S. Buena Vista St., Burbank, CA 91505
OC	Fountain Valley Community/ Fountain Valley Regional Hospital-The Center for Breast Care	53.7%	11190 Warner Avenue, Suite 214, Fountain Valley
OC	St. Joseph Orange	9.3%	1100 West Stewart Drive, Orange, CA 92868
OC	Kaiser Anaheim	4.6%	OC Anaheim Medical Center, 3440 E La Palma Ave. Anaheim, CA 92807 & KP Anaheim Medical Center (Women's Health Services), 441 N. Lakeview Ave., Anaheim, CA 92807
OC	*OLD name:* FHP Fountain Valley -->*NEW name:* Orange Coast Memorial	4.3%	9920 Talbert Avenue, Fountain Valley, CA 92708-5153
OC	Hoag Memorial Presbyterian/Hoag Family Cancer Institute Patty & George Cancer Center	4.1%	One Hoag Drive, Newport Beach, CA 92663
OC	UC Irvine Healthcare	4.1%	101 The City Drive South, Orange, CA 92868

OC	Garden Grove Medical	3.1%	12601 West Garden Grove Boulevard, Garden Grove, CA 92843
OC	St. Joseph Health - St. Jude Medical Center	Not available	101 E. Valencia Mesa Dr., Fullerton, CA 92835
OC	St. Jude Heritage Medical Group	Not available	2151 N. Harbor Blvd., Suite 3200, Fullerton, CA 92834-4138
KEY			
Yellow	Duplicate between geographic area		Total = 1
Green	Available PNP (LA-CSP & web search overlap)		Total = 4
Orange	Web Search Only		Total = 4

LA = Los Angeles *OC = Orange County* *SEA = Southeast Asians*

- The Facilities List was from the Los Angeles Cancer Surveillance Program (LA-CSP) and generated by Dr. Ann Hamilton, Associate Professor of Research at the University of Southern California, who holds administrative oversight over the use of registry data through the LA-CSP.
- Data involved frequency counts of female Southeast Asian (SEA) and non-Hispanic white (NHW) breast cancer patients, residing in the Los Angeles (LA) and Orange County (OC) regions during the 2000-2005 and 2006-2010 time periods.
- The hospital data from these specific LA-CSP case listings were reviewed to distinguish and identify facilities (n=20) that served at least 2-3% of SEA women diagnosed with invasive breast cancer.
- Additional health care facilities with PNPs were identified through a web-based search (n=4).
- The list obtained from the LA-CSP and the list generated from online research were compared to determine if there was any overlap between facilities (n=4), where patients actually accessed care and institutions that offered PN services and to showcase the variance in availability of PNPs.
- The “Facilities List” indicates the contact information (i.e. facility address and phone numbers for patient-centered departments) for each health care facility identified through the LA-CSP and web-based research. This list was also expanded and utilized as a call log to document notes and tasks from phone conversations, as well as record the availability of PNPs and permissions received to access LA-CSP data.

Appendix 3.2 – Short Telephone Questionnaire

SHORT TELEPHONE QUESTIONNAIRE

These questions refer to the patient-centered care programs available at your facility. Some questions will specifically reference "patient navigators", but the term used at your facility may range from "lay health worker", "patient advocate" or "nurse navigator". Please answer the questions to the best of your ability using the terms used at your facility.

Facility Name: ______ **Date: ______**

1. Does your facility currently have a cancer navigation program in place to assist patients after receipt of a breast cancer diagnosis?
   ☐ Yes → Please answer Questions #2-6
   ☐ No → Thank you.

2. When was the program first established? ***{C-Y}***
   Month ______ Year ______
   {Prompts: 5 years ago, 10 years ago, more than 10 years ago}

3. What was the impetus for establishing a program? (Please check all that apply) ***{C-Y}***
   ☐ Patient need
   ☐ Facility need
   ☐ Legislation
   ☐ Compliance with certification requirements
   ☐ Research project
   ☐ Other - please specify ______

4. Was the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (NOA) related to the establishment of the program?* ? ***{C-Y}***
   ** The NOA granted the Secretary of Health and Human Services the authority to award funds for the establishment of patient navigation programs over a five-year period.*
   ☐ Yes
   ☐ No
   ☐ Don't Know

5. At what stage in the health care process are patient navigators assigned/matched with a patient with breast cancer? ***{E-Y}***
   - ☐ Screening
   - ☐ Diagnosis
   - ☐ Treatment
   - ☐ Post-Treatment/Follow-up
   - ☐ Other - please specify ______

6. Does your cancer patient navigation program provide cultural and linguistic services to the following Southeast Asian Ethnic groups? (Please check all that apply) ***{C-Y}***

		Cultural	Language	Other
a.	☐ Cambodian When was the program first established? ***{C-Y}*** Month ______ Year ______	☐	☐	☐
b.	☐ Lao When was the program first established? ***{C-Y}*** Month ______ Year ______	☐	☐	☐
c.	☐ Thai When was the program first established? ***{C-Y}*** Month ______ Year ______	☐	☐	☐
d.	☐ Vietnamese When was the program first established? ***{C-Y}*** Month ______ Year ______	☐	☐	☐

These are all the questions I have for today. Thank you for your time and assistance!

Appendix 3.3 – Initial Script to Contact Facilities

Initial Script to Contact Facilities

INTRODUCTION

Hello, my name is Annalyn Valdez-Dadia and I am a doctoral student at the UCLA Fielding School of Public Health. I am conducting a research study to understand patient-centered care programs, particularly navigation programs aimed at assisting Southeast Asian breast cancer patients.

Would you be able to assist me?
{*If YES*} May I schedule a 15-minute phone meeting with you to discuss my study and conduct a brief questionnaire?
{*If NO*} Who is the best person to call? May I have their name and contact number?
{*If referred to someone, use same script above to schedule phone meeting.*}

Appendix 3.4 – Facility Survey

FACILITY SURVEY

These questions refer to the patient-centered care programs available at your facility. Some questions will specifically reference "patient navigators", but the term used at your facility may range from "lay health worker", "patient advocate" or "nurse navigator". Please answer the questions to the best of your ability using the terms used at your facility.

Facility Name: ______ **Date: ______**

1. Who does the patient services program target? (Please check all that apply) ***{C-Y}***
   - ☐ Underserved/Uninsured
   - ☐ Low-income
   - ☐ Age groups - please specify: ______
   - ☐ Ethnic/Language groups - please specify: ______
   - ☐ Cancer types - please specify:
     ☐Breast ☐Colorectal ☐Cervical ☐Lung ☐Prostate ☐Other
   - ☐ Other - please specify: ______

2. What types of services are provided? (Please check all that apply) ***{C-Y}***
   - ☐ Scheduling appointments
   - ☐ Transportation to/from appointments
   - ☐ Assistance with health care related paperwork (e.g. insurance forms)
   - ☐ Finances
   - ☐ Education
   - ☐ Access to screening services
   - ☐ Access to diagnostic services
   - ☐ Access to treatment services
   - ☐ Access to post-treatment services
   - ☐ Counseling
   - ☐ Chronic disease self-management support
   - ☐ Pain management
   - ☐ Other - please specify ______

3. How are patients managed through this system? (Please check all that apply) ***{C-Y}***
   - ☐ Assistance from screening to diagnosis
   - ☐ Assistance from diagnosis to treatment
   - ☐ Assistance from treatment to post-treatment/follow-up
   - ☐ Other - please specify ______

4. What level of support is provided?
   - ☐ Patient navigator acts as case manager through ALL visits
   - ☐ Patient navigator acts as case manager during cancer related visits
   - ☐ Patient navigator visits only upon request
   - ☐ Other – please specify:

5. What led to the development of the program? (Please check all that apply) ***{C-Y}***
   - ☐ An individual – please specify name ______
   - ☐ Community advocates (e.g. cancer survivors, community agency staff, etc.)
   - ☐ Facility staff (e.g. Program Coordinators, Facility Managers, etc.)
   - ☐ Administration (e.g. Hospital administrators, etc.)
   - ☐ Healthcare professionals (e.g. Nurses, Physicians, etc.)
   - ☐ Volunteers - please specify ______
   - ☐ Other - please specify ______

6. How did program leaders assist/help in the development of the program? (Please check all that apply) ***{F-Y}***
   - ☐ Development of ideas/program
   - ☐ Obtain funding
   - ☐ Obtain facility approval to administer program
   - ☐ Create training curriculum
   - ☐ Recruitment
   - ☐ Identification of navigators
   - ☐ Marketing
   - ☐ Other - please specify ______

7. What types of resources and/or tools did program leaders use during the development of the program? (Please check all that apply) ***{F-Y}***
   - ☐ Community meetings
   - ☐ Flyers
   - ☐ Fundraisers
   - ☐ Training curriculum
   - ☐ Other - please specify ______

8. Did you receive any funding to support the program? ***{C-Y}***
   - ☐ Yes
   - ☐ No
   - ☐ Don't Know
     a. If yes, what was the funding source? ______
     b. If yes, did you have ongoing funding to support the program?
        - ☐ Yes – please specify how funding is maintained
          - ☐ Donations
          - ☐ Grant funds
          - ☐ Hospital operational funds
          - ☐ Medicaid reimbursement
          - ☐ Other – please specify: ______
        - ☐ No
        - ☐ Don't Know

9. What type of patient navigators do you use? (Please check all that apply) ***{F-Y}***
   - ☐ Lay health workers
   - ☐ Peer navigators
   - ☐ Nurse navigators
   - ☐ Social Workers
   - ☐ Patient Advocates
   - ☐ Other - please specify ______

10. Do you also use volunteer (unpaid) patient navigators?
    - ☐ Yes
    - ☐ No
    - ☐ Don't Know

11. How many full-time equivalent (FTE) patient navigators do you use? ***{E-Y}***

____

☐ Don’t Know

12. Are patient navigators paid? ***{F-Y}***

☐ Yes
☐ No
☐ Don’t Know

    a. If yes, how are patient navigators paid?

       ☐ By a community-based agency
       ☐ By the hospital/healthcare facility
       ☐ By health insurance companies
       ☐ Other - please specify _______

13. How many patients have participated in your navigation program in 2011? ***{E-Y}***

# of new patients _______
# of patients who received services _______
☐ Don’t Know

    a. How many are breast cancer patients?

       ____

       ☐ Don’t Know

    b. How many are Southeast Asian (e.g. Cambodian, Laotian, Thai, Vietnamese)?

       ____

       ☐ Don’t Know

14. Do your patient navigators receive any type of training? ***{F-Y}***

☐ Yes
☐ No
☐ Don’t Know

    a. If yes, what type of training is required?

       ____

       ☐ Don’t Know

15. What are the requirements to become a patient navigator? (Please check all that apply) ***{F-Y}***
    - ☐ Certification program
    - ☐ Bachelor degree
    - ☐ Master degree
    - ☐ Nursing license
    - ☐ Ethnic/Language group
    - ☐ Other - please specify ______

16. How are patient navigators assigned or matched with a patient? (Please check all that apply) ***{E-Y}***
    - ☐ Ethnicity
    - ☐ Language
    - ☐ Geographic area
    - ☐ Cancer type
    - ☐ Stage at diagnosis
    - ☐ Type of treatment modality
    - ☐ Other - please specify ______

17. Are there mechanisms to assess the timely receipt of treatment of the patient? ***{E-Y}***
    - ☐ Yes
    - ☐ No
    - ☐ Don't Know

    a. If yes, how is feedback provided?
        - ☐ Chart notes
        - ☐ Surveys
        - ☐ Other – please specify ______
        - ☐ Don't Know

18. Are any mechanisms in place to assist patients if additional services are needed? ***{C-N}***
    - ☐ Yes
    - ☐ No
    - ☐ Don't Know

a. If yes, what additional services do you provide?
   ______

b. If yes, do you refer patients to other services?
   ☐ Yes – please specify ______
   ☐ No
   ☐ Don't Know

c. If no, what were the reasons for NOT providing additional assistance mechanisms? (Please check all that apply) ***{C-N}***
   ☐ Did not have sufficient patient need/demand
   ☐ Did not have financial resources
   ☐ Did not have sufficient staff
   ☐ Did not have enough time to plan
   ☐ Other – please specify ______

19. Were there any barriers in the development of a patient assistance program? ***{F-N}***
   ☐ Yes
   ☐ No

a. If yes, what were those barriers?
   ☐ Did not have financial resources
   ☐ Did not have sufficient staff
   ☐ Did not have sufficient patient need/demand
   ☐ Did not have enough time to plan
   ☐ Other – please specify ______

Thank you for your time and assistance!

Appendix 3.5 – Permission Request Message

<u>Permission Request Message</u>

(Will be sent by email)

Dear *{name of facility administrator}*,

Thank you again for participating in the telephone questionnaire!

As previously discussed, aggregated hospital data from your facility will help me gain a better understanding about Southeast Asian women with breast cancer who were diagnosed and/or treated at your facility over a 10 year period (between 2000 to 2010).

At your earliest convenience, please select "REPLY ALL" to this message and check one of the options below:

_____ I am representing _______________ hospital and we **<u>AUTHORIZE</u>** the Los Angeles Cancer Surveillance Program permission to provide Ms. Annalyn Valdez-Dadia with aggregated data on numbers of and other information about Southeast Asian women with breast cancer who have been diagnosed or treated at this hospital over the last 10 years (2000-2010) for her dissertation study.

_____ I am representing _______________ hospital and we **<u>DO NOT AUTHORIZE</u>** the Los Angeles Cancer Surveillance Program to provide Annalyn Valdez-Dadia with aggregated data for her dissertation study.

Thank you for your time and assistance!

Sincerely,

Annalyn Valdez-Dadia, MPH
Doctoral Student
Health Policy & Management
UCLA Fielding School of Public Health

Appendix 3.6 – Process for Administering Facility Survey & Permission Request

1) Ask which method of correspondence key personnel prefers for the “Facility Survey” and the “Permission Request Message”, then obtain mailing address or email address for each type of correspondence

2) Mail the “Facility Survey” along with the “Cover Letter-Facility Survey”, by regular mail or electronically, and ask key personnel to complete and return within two weeks

3) Ask if key personnel or another person would be able to respond to the “Permission Request Message” and obtain the individual’s email address

4) Send “Permission Request Message” electronically to identified personnel and ask individual to reply to both the study researcher and LA-CSP

5) A follow-up phone call will be performed and/or an email message will be sent if the “Facility Survey” is not returned after the two-week period and/or if no response is received for the “Permission Request Message” after the two-week period

6) An additional 2 attempts to follow-up will be conducted for the “Facility Survey” and 3 attempts will be conducted for the “Permission Request Message”

7) Follow-up contact ends if no response is received and the process is documented on the “PNP List”

Appendix 3.7 – Cover Letter for Facility Survey

Date

RE: Facility Survey for A. Valdez-Dadia Dissertation

Dear {name},

Thank you for agreeing to complete this questionnaire. The information you provide will contribute to my dissertation research. As previously discussed, the purpose of this study is to understand how patient navigation or care coordination programs were developed and how they function at your facility. The data collected from this questionnaire will be used to understand how patient assistance programs can be integrated into the U.S. health care system and how these types of patient-centered programs have assisted cancer patients through their cancer experience, particularly Southeast Asian (Cambodian, Laotian, Thai and Vietnamese) breast cancer patients.

This questionnaire will take approximately 15-30 minutes to complete. Please answer the questions to the best of your ability. There are no right or wrong answers. Your participation in this questionnaire is completely voluntary. After completing the questionnaire, please return to me using the enclosed self-addressed, stamped envelope. If I do not receive your questionnaire at the end of two weeks, I will follow-up with a phone call.

I am very grateful to you for the time you are taking to complete and return this questionnaire!

Sincerely,

Annalyn Valdez-Dadia, MPH
Doctoral Candidate
UCLA Fielding School of Public Health
Department of Health Policy and Management

Appendix 3.8 – Patient Demographic Variables

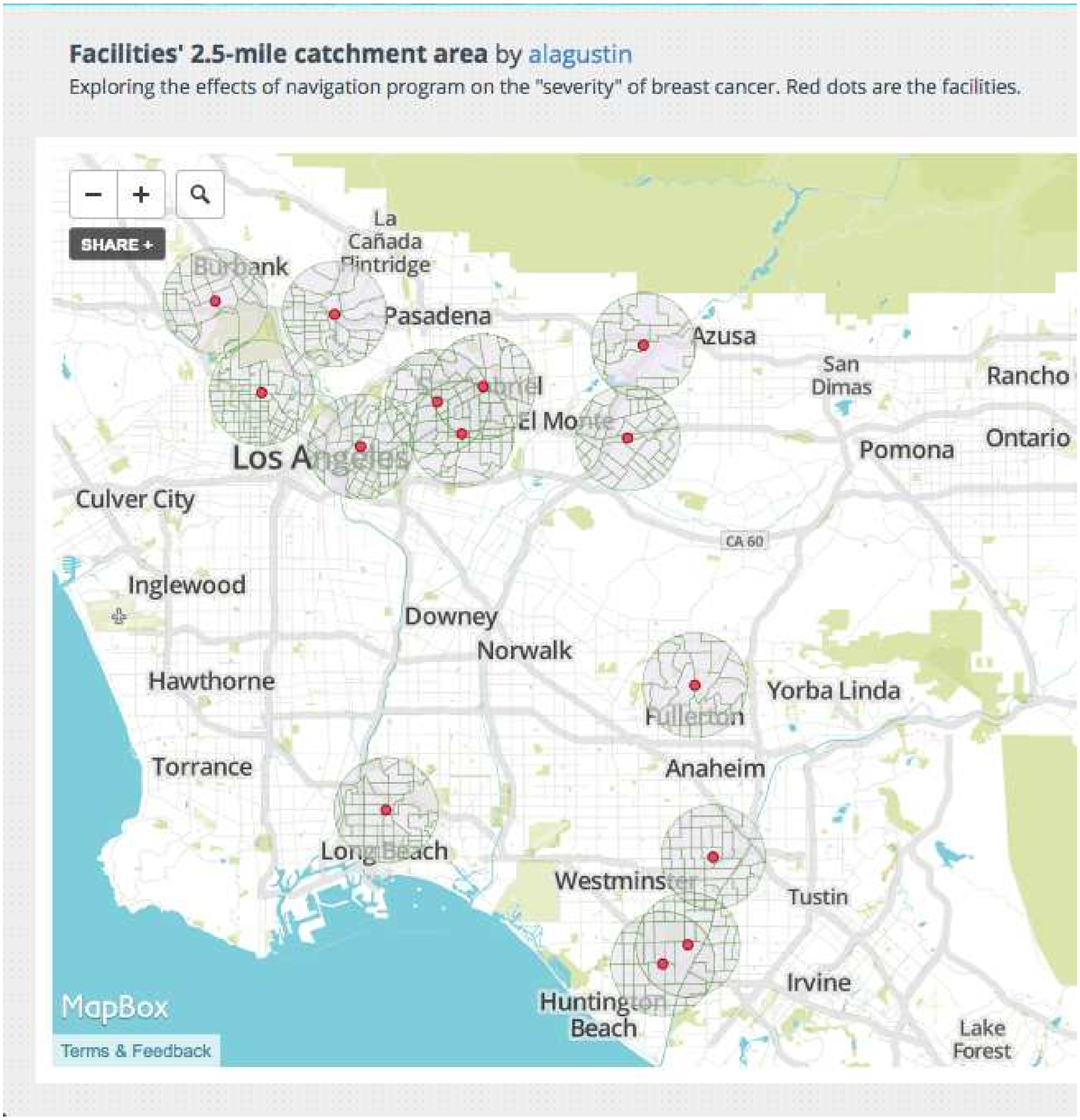
Variable Name	Definition	Justification for need
AGE	Age at diagnosis	Limit to age 35+
BIRTHPL	Birthplace	Descriptive
CENSUS00	Census tract of address at time of diagnosis based on the 2000 U.S. Census.	Descriptive
COLLEGE	Proportion of those 25+ years with a college degree	Descriptive
COUNTY	California county of residence	Limit to Los Angeles & Orange counties
DOB	Date of birth of patient	Descriptive
EDINDEX	Average years of schooling	Descriptive
INDUS80	Type of industry or business associated with the patient's longest-held occupation at time of diagnosis	Descriptive
NOEDUC	Proportion of those >=25 years without a high school diploma	Descriptive
NOJOB	Proportion of those >=16 years in the labor force that is unemployed	Descriptive
MARSTAT	Marital status when patient was first diagnosed	Descriptive
MDINC	Median household income	Descriptive
PAYER	Payer at diagnosis	Descriptive
QUINYOST	Socioeconomic status	Descriptive
RACE1	Race/ethnicity of the patient	Limit to Cambodian, Laotian, Thai, Vietnamese & non-Hispanic white
RELIGION	Patient's religion at time of diagnosis	Descriptive
SEX	Sex of the patient	Limit to Females
STAGE	Stage at diagnosis	Descriptive
SUMSTAGE	Summary stage at diagnosis	Descriptive

Appendix 3.9 – Outcome Variables

Variable Name	Definition	Justification for need
DATEADM	Date patient was first seen at hospital for evaluation/treatment of tumor	Outcome measure
DATEDX	Date of diagnosis	Outcome measure
DTDEFSURG	Records the date of SURGPRIM, the most definitive surgical resection of the primary site performed as the first course of treatment	Outcome measure
DTSYSTEMIC (non-surgical treatment)	Records the date of initiation for systemic therapy that is part of the first course of treatment	Outcome measure
MARKERCA	Breast cancer tumor marker for California-1. (ER, HER2)	Descriptive
HISTO_M2	Fifth digit of the ICD-O-2 morphology code – indicates the malignancy or behavior of this tumor	Limit to “in situ” and “malignant/ invasive”
HOSPNO (reporting)	Unique code for the hospital/facility with the earliest admission date for this tumor	Determine type of facility
HOSPNO (for treatment)	Unique code for the hospital/facility of treatment	Determine type of facility
RXDATE (non-surgical treatment) ***rx_mth_calc2***	Date first course of definitive treatment started *Months between diagnosis and 1st course definitive treatment started (calc by days/30)*	Outcome measure
RXDATEC (non-surgical treatment) ***chemo_mth_calc***	Date chemotherapy started *Months between diagnosis and chemo therapy started (calc by days/30)*	Outcome measure
RXDATEH (non-surgical treatment) ***horm_mth_calc***	Date hormone therapy started *Months between diagnosis and hormone therapy started (calc by days/30)*	Outcome measure
RXDATEi (non-surgical treatment)	Date immunotherapy started	Outcome measure
RXDATEO (non-surgical treatment)	Date other therapy started	Outcome measure
RXDATER (non-surgical treatment) ***rad_mth_calc***	Date radiation therapy started *Months between diagnosis and radiation therapy started (calc by days/30)*	Outcome measure
RXDATESN	Date when procedure for diagnostic or staging purpose was performed	Outcome measure
SURGDATE ***surg_mth_calc***	Date the earliest definitive surgery was performed *Months between diagnosis and earliest definitive surgery (calc by days/30)*	Outcome measure
SURGPRIM	Most extensive type of surgery performed during the first course of treatment for the tumor	Outcome measure
SURV_TIME	Survival time in months	Descriptive
CHEMOSUM	Identifies the type of chemotherapy given as first course of treatment at this and all other facilities. If chemotherapy was not first course of treatment, codes are provided to record that reason	Descriptive
TRANSSUM	Identifies systemic therapeutic procedures given as first course of treatment at this facility and all other facilities or the reason why they were not used	Descriptive
DATEOFCONCLUSIVEDX	Documents the date when a conclusive cancer diagnosis (definite statement of malignancy) is made following an initial diagnosis that was based only on ambiguous terminology	Descriptive

VARIABLE NAME = Original outcome measures ; **variable_name** = Calculated and recoded variables

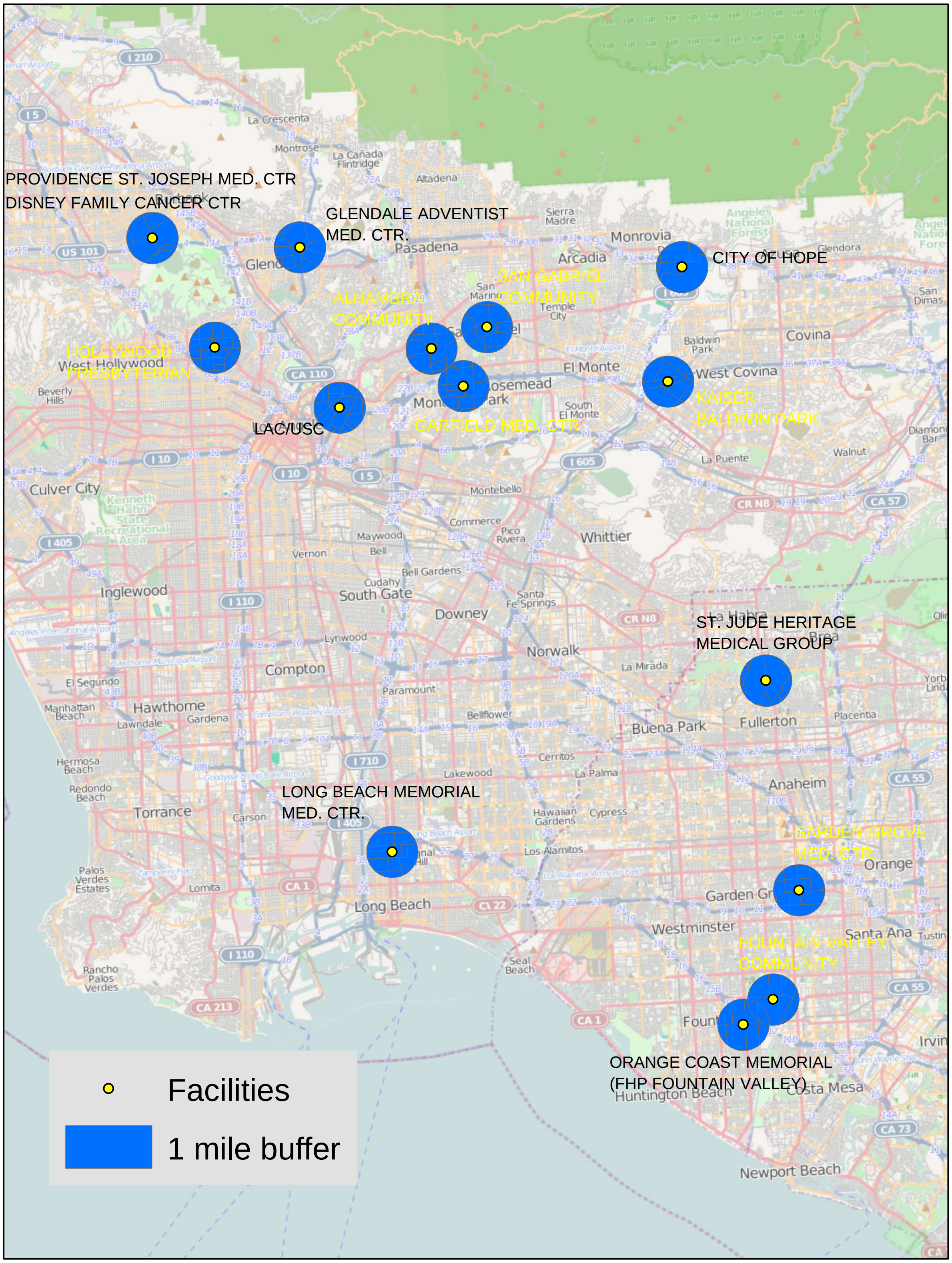
Appendix 3.10 – Map of 2.5-mile Catchment Area



Facilities' 2.5-mile catchment area by alagustin

Exploring the effects of navigation program on the "severity" of breast cancer. Red dots are the facilities.

Appendix 3.11 – Map of 1-mile Catchment Area



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CHAPTER 4

Practitioner Perceptions of Patient Navigation Programs (Study 2)

4.1 – Abstract

Purpose: Patient Navigation Programs (PNPs) continue to be a relatively new strategy for addressing health care disparities in the cancer care arena. Although cancer patients and caregivers appear to report high satisfaction with current navigation programs, few studies have explored the perceptions of health care practitioners and the impact of PNPs on access to and utilization of cancer care services. This study examines the practitioners' experiences with PNPs and describes the practitioner and institution's viewpoint on the value of patient navigators. This information may also provide research advocacy networks with evidence to inform stakeholders of the need for further research on the utility of patient navigators, especially among immigrant populations, including Southeast Asians (SEA).

Methods: Secondary analysis of 23 semi-structured interview transcripts with 14 practitioners and 9 patient navigators was conducted using a web-based qualitative and mixed-methods data management program. Transcripts were coded to identify primary research themes and used to develop a codebook. Qualitative web-based analytical tools were used to review and analyze the data for frequency of coded themes, code co-occurrence, and develop a conceptual model.

Results: Exploration of practitioner perspectives revealed support of PNPs and the benefit of patient navigation services for assisting SEA breast cancer patients with utilization of cancer care services. Health care practitioners positively viewed patient navigation services and referred to navigators as the "bridge" in enhancing patient-physician communication and fostering access to cancer care services. Examination of navigator perceptions highlighted the

challenges they encountered in assisting SEA patients with functional tasks at the systems level. Fear, lack of knowledge about breast cancer services, and trust in health care providers were the primary challenges SEAs encountered. Navigators indicated that supporting and encouraging patients, as well as establishing trust with patients and practitioners were instrumental in improving the patients' readiness to access and obtain services.

Conclusions: In this study, patient navigators and health care practitioners agreed that incorporating PNPs at the system level would be of benefit for breast cancer patients with limited English proficiency and insufficient knowledge about the U.S. health care system. Patient navigators provide functional and emotional services that enable SEA patients to better understand the importance of breast health and the proactive approaches they can take to access breast cancer care services. Advocating for a policy level approach would be an essential strategy in the process of disseminating and sustaining PNPs, especially in programs targeting low-income and under-served communities, such as SEAs. Future research should assess the approaches for reducing barriers and challenges to the adoption and integration of PNPs, such as administrative and financial support, through, for example, adequate insurance reimbursement.

4.2 – Introduction

A 1989 report derived from the American Cancer Society's national hearings on cancer among the poor contributed to the establishment of the first formal and published study of a patient navigation program (PNP) in 2001 by Dr. Harold Freeman at the Harlem Hospital Center in New York City (Freeman & Rodriguez, 2011). Positive outcomes from the Harlem intervention have since contributed to the evolution of PNPs as a mechanism to address issues of cancer care disparities. More importantly, independent establishment of various PNPs in cancer care institutions and community-based organizations nationwide influenced the enactment of the Patient Navigator Outreach and Chronic Disease Prevention Act (NOA) in 2005 and the development of PNP guidelines by the American College of Surgeons-Commission on Cancer (American College of Surgeons, 2012).

Over the last decade, studies investigating the efficacy of PNPs have focused on the perspectives of the patients and PNP staff (Korber, Padula, Gray, & Powell, 2011; Lee et al., 2011; Yosha et al., 2011). However, the practitioners' perceptions of patient navigators or PNPs have been understudied. Other areas where more research is needed is to determine if PNPs improve access to cancer care or enhance communication between patients and practitioners. Ultimately the goal would be to determine if PNPs contribute to better patient outcomes and patient-practitioner satisfaction with care in a cost effective way.

Attempts to demonstrate the cost-effectiveness of PNPs have indicated that PNPs improve access to diagnostic resolution, reduce direct medical costs and contribute to a reduction in productivity losses, but overall findings were inconclusive and lacked consensus on program impact, dissemination and sustainability due to the diverse measures used to assess cost-effectiveness (i.e. program costs, quality-adjusted life-year, survival rates, or earlier cancer stage at time of diagnosis) and the heterogeneity of available programs nationwide (Bensink et al., 2013; Markossian & Calhoun, 2011; Ramsey et al., 2009; Whitley et al., 2011). The gaps in research and lack of more definitive evidence on the effectiveness of PNPs has hampered efforts to increase the availability of PNPs at health care service institutions due to limited financial and administrative support to move from program conception to actual implementation and sustainability.

Previous studies have evaluated individual patient level perspectives, focusing on patient experiences and patient perceptions of PNPs, and found that patients value patient navigators because they provide educational information, enhance better patient-physician communication, and provide emotional support and personalized care (Carroll et al., 2010; Donelan et al., 2011; Korber et al., 2011). Studies have also investigated the role of PNPs from the perspective of the navigators themselves, which indicate the importance of providing informational and instrumental (e.g. identification of financial resources and patient-physician communication) support (Jean-Pierre et al., 2011; T. Nguyen, Tanjasiri, Kagawa-Singer, Tran, & Foo, 2008). Only one study was found that conducted a multi-perspective analysis of PNP, which linked interviews of patients with their navigator. The study by Yosha, et al., consisted primarily of non-Hispanic white (NHW) patients and navigators, illuminated the interpersonal struggles between patients and navigators, such that navigators wrestled between supporting patients who did not follow medical advice and being invested in their well-being, while patients were comfortable with their decisions and were unaware of their navigator's perspective (Yosha et al., 2011).

Additionally, research that investigated perspectives on PNPs have often been conducted among patients at various points on the cancer care continuum. In the study by Yosha and colleagues, patients were identified as newly diagnosed breast and colorectal cancer patients who were navigated through the completion of active cancer treatment. Research by Nguyen, et al. involved patients who were navigated through the breast and cervical screening process (T. Nguyen et al., 2008), while the study by Donelan and colleagues involved breast cancer patients receiving navigation services at a breast center after an abnormal mammogram (Donelan et al., 2011). The difference between these studies alludes to the diverse roles and responsibilities placed on navigators and the varying degrees of adjustments they undertake when coordinating cancer care services for patients at different stages on the cancer continuum.

The type of resources and services delivered by patient navigators, and the utility of aid given by this group of health care advocates has often been evaluated from either the patient's perspective or measured through access and utilization of services, such as percentage of patients screened and number completing treatment (Donelan et al., 2011; Fiscella et al., 2011; Koh, Nelson, & Cook, 2011). Methods for evaluating the benefits and advantages in support of PNPs have seldom been assessed through the perspective of practitioners. More specifically, the opinions and experiences of practitioners who provide health care services to immigrant groups, such as SEAs, is needed to examine the potential value of PNPs among culturally and linguistically challenged communities, and to provide evidence in support of the adoption and integration of PNPs into the U.S. health care system.

4.2.1 Background on Study by Nguyen et al.

In 2008, Dr. Tu-Uyen Nguyen and colleagues conducted a study that involved focus groups with navigated patients, and individual interviews with community based health navigators (CBHNs) and practitioners with the goal of developing a curriculum for patient navigators. The study by Nguyen et al. was guided by the following research questions:

1. *What are the important individual, interpersonal and community factors a breast health navigation program should address?*
2. *What types of culturally tailored strategies CBHNs provide support and enable SEA women to obtain necessary services throughout the cancer care continuum?*
3. *What specific training elements are needed in a community-based navigation program curriculum to prepare CBHNs to be effective in their role of promoting breast health?*

Research findings indicate that all four SEA sub-groups (Cambodian, Laotian, Thai and Vietnamese) shared similar concerns about the complexities of the current U.S. health care system, and each group found navigators were invaluable in bridging the gap to access health care services (Orange County Asian and Pacific Islander Community Alliance (OCAPICA), 2009). Results from the focus groups conducted with patients was developed into a report that summarized each SEA community's 1) general health needs, 2) resources for breast health care assistance, 3) knowledge of navigation services, 4) types of navigation services provided, 5) communication with practitioners, 6) beliefs regarding the qualities and skills desired for navigators, and 7) suggested changes and improvements for the navigation program (Orange County Asian and Pacific Islander Community Alliance (OCAPICA), 2009).

Nguyen elaborated on the findings from the three groups by describing the perspectives of each on the use of navigation services. Analysis of the transcripts found that navigated participants acknowledged that the support and physical presence of navigators increased their confidence to engage in their own health care (T. N. Nguyen, Tran, Kagawa-Singer, & Foo, 2011). The CBHNs felt that their most important role was providing functional support, such as translating/interpreting information, filling out forms and providing assistance with and to appointments (T. N. Nguyen et al., 2011). The practitioners saw the value of navigators in alleviating the challenges (e.g. inability to relay the importance of treatment adherence) they faced when working with diverse communities (T. N. Nguyen et al., 2011). Each set of findings, however, illuminates the findings at the individual level for each constituent group.

4.2.2 Research Questions & Aims

This analysis of patient navigator and practitioner perspectives is one of the first studies to attempt to understand the value of PNPs at the system level. The perceptions of practitioners and patient navigators themselves would add to the literature on PNPs by highlighting the factors these individuals identify are important in addressing cancer health disparities from the health system standpoint. For instance, assessing congruence with patients and new immigrant groups in terms of the services they need and what the health care system provides, or challenges that would inform the organizational structure about cancer care services. Practitioners and patient navigators also have a better insight into the gaps that exist in the current health care system. The findings generated through this process could inform stakeholders of the benefits and challenges of PNPs, and provide insights into promising approaches for the integration and adoption of PNPs into clinical settings at the systems level.

This dissertation study was designed to address the lack of evidence on the perceptions of practitioners regarding patient navigation and the perceptions of navigators working with immigrant SEA breast cancer patients. Therefore, the two research questions for this study were:

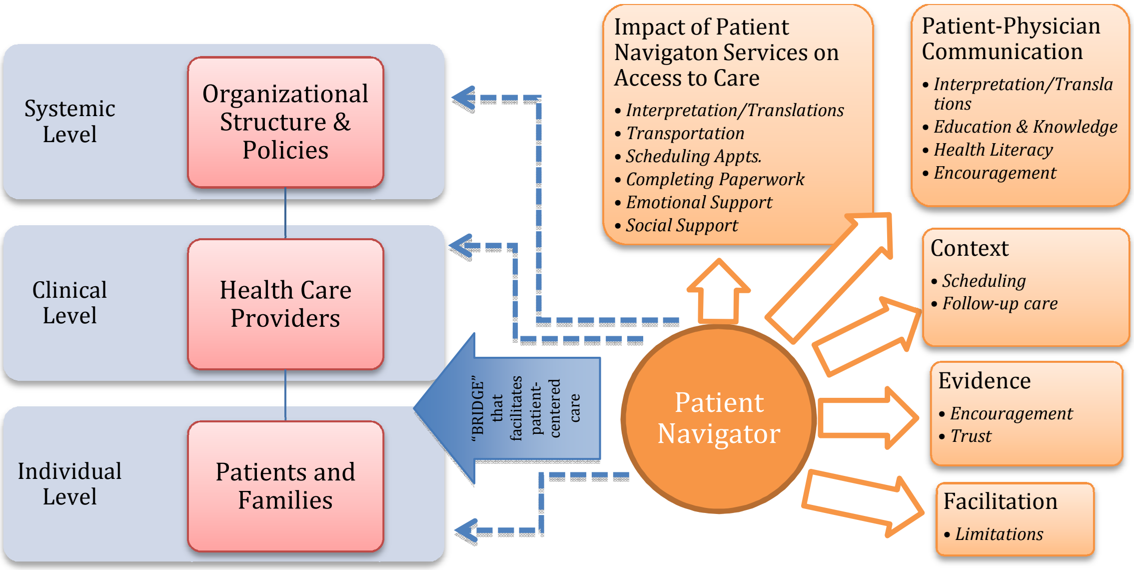
1) *How do practitioners and navigators perceive the impact of patient navigation services on access to care and patient-physician communication?*
2) *Do the perceptions of health care practitioners convey evidence needed for research advocacy networks, such as the Asian American Network for Cancer Awareness Research and Training (AANCART), to build on for further research in patient navigation and for practitioners to support the adoption and integration of PNPs into health services?*

Using transcripts from the research conducted by Dr. Tu-Uyen Nguyen, this study presents the views and experiences of practitioners who have encountered and used patient navigators when treating SEA breast cancer patients, as well as the perceptions of the patient navigators who have assisted members of the diverse SEA communities of Los Angeles and Orange counties. This study investigates the practitioners' perceptions of barriers to the receipt of timely care, focusing specifically on the interval between diagnosis and first course of treatment.

4.2.3 Theory Development

Practitioner support for the adoption and integration of PNPs would enhance the current literature by illustrating the system-wide advantages of patient navigators and utility of patient navigation programs in improving access to cancer care services. A conceptual framework depicting the relationships assessed in this dissertation is found in Figure 4.1-Conceptual Framework for Perceptions of PNP Stakeholders and was developed based on findings from the analysis of interview transcripts. The current U.S. health care system is divided into three levels (system, clinical, and individual), which form a hierarchy of how health care services are delineated and distributed from the organization down to patients. As displayed in the framework and supported in the literature, patient navigators provide a range of functional services to assist patients access appropriate cancer care services. Secondary analysis of interviews indicates that patient navigators often serve as a "bridge" between clinicians and patients. Yet, they can also be incorporated at both the clinical and systems level to standardize the accessibility of health care services for breast cancer patients.

Figure 4.1 – Conceptual Framework for Perceptions of PNP Stakeholders



In this study, patient navigation services encompass more than an individual role, but was conceptualized as a possible service that could be incorporated at the clinical or system level to facilitate access to care and enhance the effectiveness of patient-physician communication.

4.3 – Materials and Methods

4.3.1 Study Design

Ethnography is a qualitative approach that emphasizes a focus on studying an entire culture. The concept of ethnography has been applied to not only investigate notions of ethnicity and geographic location but specific groups and organizations (Trochim, 2006). This study applied an inductive and deductive qualitative approach to explore the experiences and views of practitioners as it relates to the use of patient navigators among SEA breast cancer patients, as well as practitioner and navigator perceptions of barriers associated with the adoption and integration of PNPs into the health care system.

Inductive analysis using an iterative four-stage content analysis approach (Singleton & Straits, 2005), as described below, facilitated the interpretation of the narratives and stories expressed in the semi-structured interviews, which was used to build the story of the impact PNPs have on facilitating access to care and the integration of SEAs into the U.S. health care system.

a) Read through the interview transcripts to begin to identify emerging ideas,
b) Identify potential analytic categories and develop a codebook using a web-based data management tool,
c) Use the analytic categories to construct potential theoretical schema and models, and
d) Use theoretical themes to develop interpretations that explain the data.

Deductive analysis was then applied to assess practitioner and navigator responses in relation to the research questions. Key concepts from the Promoting Action on Research

Implementation in Health Services (PARiHS) framework (context, facilitation and evidence) (see Chapter 2 pp. 4-5) were used to compare the inductive themes and domains with the three components of the PARiHS framework. The most salient areas identified in the inductive analyses fit within the three PARiHS categories. Study themes and domains were revised accordingly.

This study evaluated the transcripts at the systems level by identifying themes associated with the impact of PNPs on access to cancer care services from both the practitioner's perceptions of the barriers and challenges encountered by patients and patient navigators in utilizing cancer care services. Contextual and facilitation barriers to the adoption and integration of PNPs in health services were also assessed. Additionally, this research attempted to understand if practitioners would support the integration of PNPs into the health care system and, if so, to also obtain evidence on the mechanisms they believe should be in place in order to encourage further adoption of PNPs.

4.3.2 Data Source & Data Collection

In 2008, Nguyen and colleagues conducted a study to document and describe the work and processes performed by CBHNs to help SEA (Cambodian, Laotian, Thai and Vietnamese) women access and utilize breast health services, with the long-term goal of developing a formal curriculum on how to train CBHNs to help women from underserved communities access breast health services (Orange County Asian and Pacific Islander Community Alliance (OCAPICA), 2009). Nguyen's study included focus groups with navigated patients and semi-structured interviews with practitioners and patient navigators serving the four SEA study groups. Practitioners were recruited through a network of health navigators from the Promoting Access to Health for Pacific Islander and Southeast Asian women (PATH for Women) program in Southern California, while patient navigators were identified through their involvement with the

PATH for Women program between 2000-2005 (Orange County Asian and Pacific Islander Community Alliance (OCAPICA), 2009).

PATH for Women was a research project funded by the Centers for Disease Control and Prevention (CDC), Racial and Ethnic Approaches to Community Health 2010 (REACH) initiative. The study included seven ethnic communities (Cambodian, Chamorro, Laotian, Thai, Tongan, Samoan, and Vietnamese) and involved a partnership between five community-based organizations and two universities. The goal of the PATH for Women project was to increase community capacity for breast and cervical cancer screenings and follow-up care among the seven communities in Los Angeles and Orange counties (Tanjasiri et al., 2004).

Transcripts of semi-structured, one-on-one, in-depth interviews from the original community-based participatory research (CBPR) project were used for this study. Specific information pertaining to recruitment and data collection of the interview transcripts can be found in Dr. Nguyen's publication about the training curriculum (T. N. Nguyen et al., 2011). The interviews were conducted with funding from the California Breast Cancer Research Program (Grant #12AB-3000), in conjunction with Families in Good Health/St. Mary Medical Center (FiGH/SMMC), Orange County Asian and Pacific Islander Community Alliance (OCAPICA), UCLA Asian American Studies Department and School of Public Health, and California State University Fullerton, Asian American Studies Program. A total of 23 in-depth, semi-structured interviews with patient navigators (n=9) and practitioners (n=14) were conducted from January through December 2008. Patient navigators were part of the REACH 2010 PATH for Women program between 2000-2005 and consisted of 9 female community-based health navigators, while practitioners consisted of physicians, nurses, radiologists, mammography technologists and physician assistants who were identified through the network of CBHNs.

University of California, Los Angeles (UCLA) Office of the Human Research Protection Program (OHRPP) permission was obtained to utilize and conduct secondary analysis of the de-identified interview transcripts from Dr. Nguyen's study. The UCLA-OHRPP institutional review board granted approval on October 16, 2012 with protocol identification number 12-001377.

4.3.3 Data Management & Analysis

The transcript analyses involved, but was not limited to, the exploration of key perspectives associated with the following interview questions from Dr. Nguyen's research interview guides:

- Practitioners (see "Appendix 4.1-Interview Guide Providers" for full list of questions):
    - #7 – How has patient navigation services affected communication between you and your patients?
    - #8 – How does having a health navigator affect your understanding of your patient's health needs?
    - #10 – How do you think health navigation services affect your patients' readiness and ability to obtain screening and/or treatment services?
    - #11 – How do you think having a health navigator affects your patients' understanding of suggested follow-up care or treatment options?
    - #12 – What aspects of health navigation do you believe are especially needed to support a patient through the cancer care continuum – from screening through diagnosis, treatment and recovery?
    - #13 – What other important functions do navigators serve for your patients? For you?
    - #16 – What are some negative aspects of having health navigators or health navigation in general?
    - #18 – What are your thoughts about incorporating patient navigation services into the health care system? How do you think this should be done?

- Patient Navigators (see "Appendix 4.2-Interview Guide Navigators" for full list of questions):
    - #1 – What services do you provide as a community-based patient health navigator?

- #4 – As a health navigator, what do you think are the most important services you provided to help women in your community access breast health care services?
- #9 – What are some negative aspects about being a health navigator or about health navigation in general?
- #11 – What are your thoughts about incorporating patient navigation services into the health care system? How do you think this should be done?

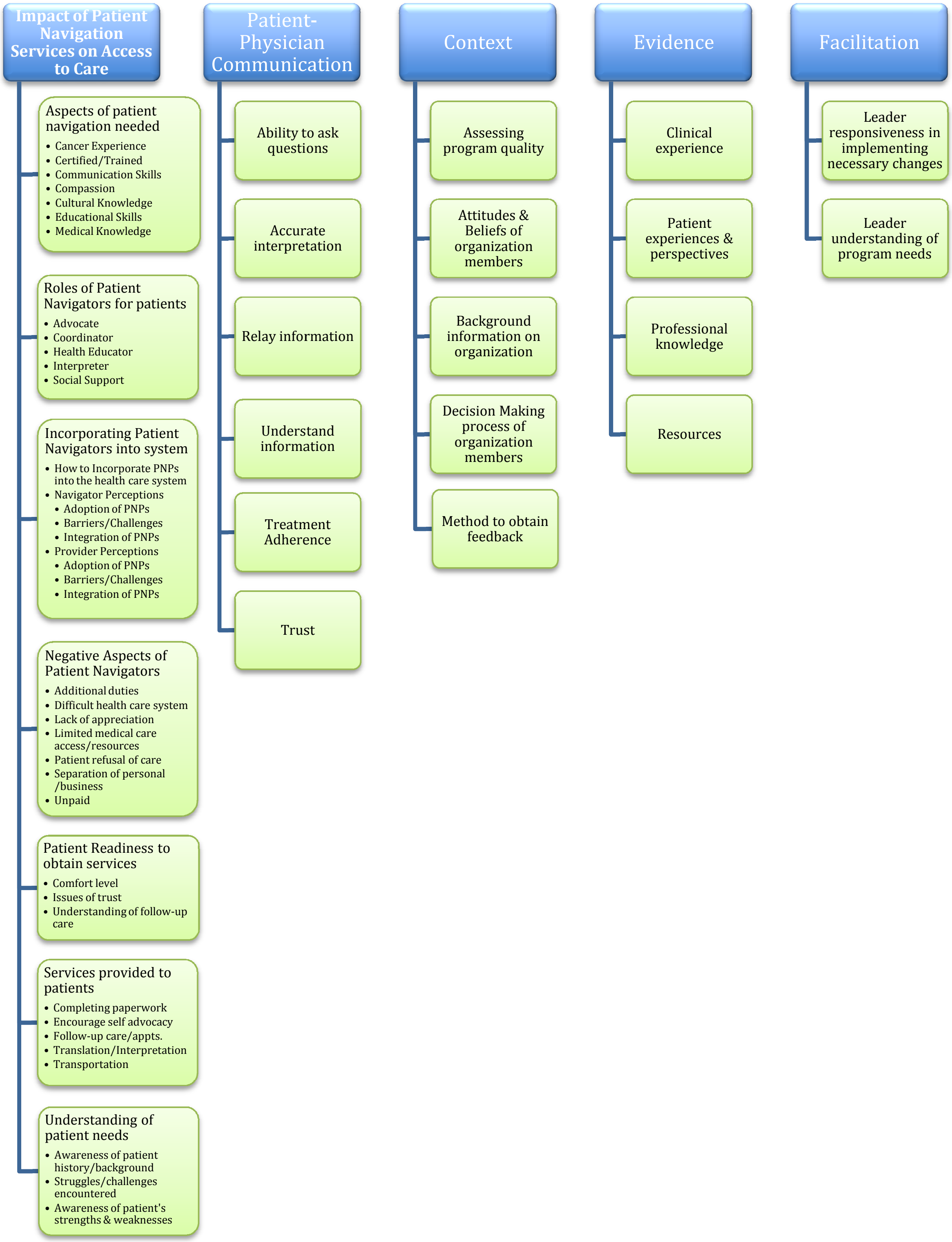
In combination with answers to other interview questions, responses to questions #16 and #18 from practitioners, and #9 and #11 from patient navigators were compared to determine whether these group of individuals shared similar views and where differences (if any) emerged.

Interview transcripts were imported into Dedoose (Version 4.5.95), a web-based data management tool for qualitative and mixed-methods research. Dedoose was developed and is operated by SocioCultural Research Consultants (SocioCultural Research Consultants, 2013). Open coding, inductive analysis, was first conducted to identify sections in the transcripts that contributed substantial information about PNPs. This initial review of the transcripts highlighted the primary research themes used, as noted in Figure 4.2-Themes.

Figure 4.2 – Themes

In-depth analysis and selective coding, using a deductive approach was then conducted to develop and organize the themes and domains, as shown in Figure 4.3-Practitioner Perspective Themes and Domains.

Figure 4.3 – Practitioner Perspective Themes and Domains



The themes and domains were entered into Dedoose and used to analyze and code the interview transcripts. Code weights are numbers assigned to a specific description and were used on a few domains to identify the type of person (i.e. practitioner, navigator, or patient) the excerpt referenced. Descriptors were also utilized to distinguish the type of interview (i.e. practitioner or navigator), professional title, gender, and characteristics of the health care facility of the interviewee (if the information was disclosed during the interview). Analytic tools in Dedoose were used to review code frequencies and code co-occurrence.

4.4 – Results

A total of 23 de-identified interview transcripts were coded: 9 navigators and 14 practitioners. Initial interview questions ascertained the title and position of the 14 practitioners: eight self-identified as medical doctors (i.e. oncologists, OB/gynecologist, internal medicine, family practice, surgeon and medical directors), two were nurse practitioners, two were registered nurses, one was a medical assistant, and one served as a radiology technician. Association with a health care facility and gender distribution of the practitioners and patient navigators could not be assessed since the data received was de-identified and information was not disclosed in most of the interviews.

Initial coding of the practitioner and navigator transcripts revealed the perceived tasks of patient navigators were primarily functional with certain levels of emotional support emerging, based on the length of the relationship between the navigator and the patient (see Table 4.1). These perceived “functional” tasks evolved from interviews with the practitioners, while elements of “emotional support” were revealed in the transcripts with navigators.

Table 4.1 – Perceived Tasks of Patient Navigators

Functional Tasks	Source of Viewpoint
1. Language interpretation/translations	Practitioners
2. Transportation	
3. Scheduling appointments	
4. Follow-up care/treatment	
5. Education & knowledge *(about the disease process and treatment requirements)*	
6. Completing paperwork	
Emotional Support	**Source of Viewpoint**
1. Companionship at appointments	Navigators
2. Encouragement	
3. Trust	

4.4.1 Impact of Patient Navigation Services on Access to Care

4.4.1.a – Services Provided to Patients: Functional Tasks

When asked to assess the 'type of services provided to breast cancer patients', health care practitioners indicated that scheduling appointments and making sure patients attended follow-up care visits were essential elements in the role of navigators,

> "I think when you have an abnormal test just making sure they get the follow-up is very helpful." ~ *Practitioner, Surgeon*
>
> "I think they {navigators} do a very good job because the patients, between the language barrier and kind of the cultural issues, with what goes on in the hospital with cancer treatment, we have so many appointments to make they really help people get through their various appointments." ~ *Practitioner, Surgeon*

Patient navigators reiterated the same sentiments by expressing the importance of getting patients to their appointments and exams. However, they also emphasized the value in helping patients understand how to access and utilize the health care system rather than just knowing what services are available. This is an essential tool for recent immigrants and helps to develop skills that fosters self efficacy,

> "…the navigator is not just playing the role that holding the hand of the patient and go to the clinic, its more than that, its preparing the patient to understand the system, to understand what they could receive from the system, what they have to do to make an effort you know getting that access

> so umm its, its very important to know that its not just you know getting the service but how to let the patient you know umm become a self sufficient person their own advocate." ~ *Navigator*

Secondary to ensuring patients followed through with necessary appointments, were the elements of translation/interpretation and transportation. Both practitioners and navigators expressed the significance of these services in accessing care for immigrant communities, especially when patients receive a positive diagnosis for breast cancer,

> "It's just so valuable to have her {navigator} there to translate; we'll call her on the phone sometimes to make appointments with patients. We'll connect three-way. Um… certainly those diagnosed with cancer and have to understand the complexity of a treatment plan and connecting from tests to physicians to surgeons to medical oncology doctors… just understanding that process can be very complex." ~ *Practitioner, Nurse Practitioner*

> "Oh they {patients} expect a lot. Number one will be um the language you know interpretation. And I would say number two: transportation."
> ~ *Navigator*

In general, this was a common perception shared by the medical practitioners, especially those working with limited English proficient patients. However, an in-depth analysis of excerpts from practitioner interviews underscores the more relevant function of navigators, which involves educating patients, such as recent SEA immigrants, about their breast health and informing breast cancer patients about the proactive approaches they can do to access the care they need to manage and maintain their health,

> "…they spend time with the {patient} to explain {to} the patients the problems and the needs for the follow up visits." ~ *Practitioner, OB/Gyn*

> "You know, immigrant, uh, they come, they are not familiar with the system…and they don't know how to navigate through it, how to get the benefit through it they should have, and so when they have someone from their own background that explain, that help them to get into the system and understand that is a sort of support, because now they are empowered and uh, and uh told how to take care of themselves." ~ *Practitioner, Medical Director*

> “…the navigator is the one who can have the inside {knowledge} of all the places and the resources, so the navigator can really introduce the patient and say ‘Okay, this is what you need to do.” ~ *Practitioner, Medical Director*

These types of statements support the need to make PNP services, available to limited English proficient communities in order to connect breast cancer patients to appropriate cancer care resources.

4.4.1.b – Services Provided: Emotional Tasks

From the navigator’s perspective, many agreed that their roles were functional, such as addressing language barriers or coordinating/directing patients to pertinent services. More importantly, they stressed the task of providing tangible and emotional support and encouragement to help SEA patients receive and follow through with the care they need, which is central to capacity building.

> “I think that the role of navigator is not to let them be worried and afraid but more to let them know that they get support and they get education and they get the information to take care of themselves.” ~ *Navigator*

4.4.1.c – Aspects of Patient Navigation Needed: Functional Tasks

With regards to specific aspects of patient navigation needed to navigate patients through the cancer care continuum, both practitioners and navigators indicated that familiarity with medical terminology and a general understanding of breast cancer care services, such as basic procedures associated with different treatment options, would be beneficial in the process of relaying information to patients with abnormal test results, especially those diagnosed with breast cancer,

> “…first of all they have to receive some sort of education about the system, community resources so they know what is available. They need to know what is available for the patient. Uh, so that’s number one…who is there willing to help. And second, they have to be proactive.” ~ *Practitioner, Medical Director*

> "Well, you have to know enough English to translate – or you need to know some medical terminology in order to provide adequate interpretation."
> ~ *Navigator*

Additionally, health care practitioners suggested that knowledge of the health care system would benefit the patient the most if the navigator possessed good communication skills, was familiar with the intricate nature of the cancer experience, and showed compassion and caring when guiding patients.

4.4.1.d – Patient Readiness to Obtain Services: Emotional Tasks

When exploring issues associated with the patients' readiness to obtain care, health care practitioners stated that the availability and presence of navigators, someone who knew the patients' language and cultural background, enabled patients to be more receptive to cancer treatment options, fostering cooperation and better health outcomes,

> "Definitely with our nurse navigator, patients feel more at ease with our therapy they have a better understanding of their disease and their therapy. We only have a limited amount of time that we can spend with our patients and so it allows patients to get more time and more information than we can offer in just one visit with a patient." ~ *Practitioner, Medical Oncologist*

> "…patient that trust you, and believe you, they will follow through with the plan…and they'll be much more compliant, and the outcome is much better. And then if you have a patient who doesn't understand you, or doesn't trust you, you, uh, doesn't feel her needs are not met, she will not follow you."
> ~ *Practitioner, Medical Director*

From the standpoint of patient navigators, the hesitancy in obtaining care stems from fears of the unknown and uncertainty in the patients' abilities to access services,

> "…there's a fear and barrier between that, for them to get the care. They get scared they go by themselves, and of course there's a fear that they don't get the right treat…the right treat from the providers, and, um, they're scared that if maybe there is something that they want to ask, they don't want to ask, and they don't feel comfortable, you know, go by themselves." ~ *Navigator*

> "…once they get diagnosed with something, they start to panic, and from there their attitude kind of changes a little bit because their expectations

> changes a little bit. They’re not sure whether they can get treated or not, they’re not sure if they can cover it {the services}.” ~ *Navigator*

Therefore, the additional time navigators took to explain cancer care procedures (i.e. exams and treatment options) to their SEA patients helped reduce anxieties and encouraged better communication and trust between the patients and practitioners. It may have also prepared them for the next steps in their cancer experience.

4.4.1.e – Barriers to Quality Care Encountered by Patient Navigation: Functional Tasks

Most of the transcripts allude to the positive aspects of PNPs and provide insightful evidence of the work that navigators do. Some of the testimonies given by practitioners articulated their understanding about the amount of work and effort needed to access cancer care services and how much they have learned about the disconnects in the health care system, and empathized with the frustrations that navigators encountered when dealing with the U.S. health care system,

> “…usually when they {patients} need expensive things {exams} we don’t have a choice but to send them to the county and {the navigator} has run into frustration after frustration at the county system. I mean here at the community hospital setting we’re able to help them much quicker and faster and more convenient than… than the county. I mean they get good care, but it just takes forever to get the test that you need.” ~ *Practitioner, Nurse Practitioner*

> “… so with her {navigator} population and with her navigation skills, it’s really opened my eyes to some of the challenges even outside of our own system and the… the real gaps in coverage.” ~ *Practitioner, Nurse Practitioner*

Although practitioners found navigators to be a valuable resource, some expressed dismay at the health care system limitations they encountered with PNPs, such as lack of availability of navigators at all health care facilities and the high turnover rate for volunteer/unpaid patient navigators,

> “It’s a huge commitment. And we could {do} recruitment and retain, retention. And that’s why all these, these programs after a short {time}, they tend to be short lived. You know, like the, I know you talk about that, and after 6 month or a year, it’s like disappear because no one can maintain it.” ~ *Practitioner, Medical Oncologist*

Only a few practitioners expressed negative comments about the services provided by patient navigators. For example, one negative aspect related to a training issue, was associated with the patient navigators’ assertiveness to provide health care services and biased opinions about the care some women might have received,

> “They want to get their job done, you know, they push, they push, they push and yet they don’t know patient don’t want it. We have to kind of you know, draw that line.” ~ *Practitioner, Medical Director-Women’s Health*

> “I try not to give patients unrealistic expectations and I think the navigator should do the same because patients are in a very fragile emotional state and when you give patients unrealistic expectations and they’re not met then they’re devastated.” ~ *Practitioner, Medical Oncologist*

Unlike the feedback from practitioners, most of the negative aspects of PNPs expressed by patient navigators themselves involved the amount of work and effort needed to guide patients through an intricate and complex health system, the difficulties in identifying affordable health care services, and knowing who to approach about available services for their community members.

> “…most negative things is just the frustration and not being able to find the patient resources, and then, uh, especially those resources that are not well established. And there hasn’t been major advocacy around, even advocacy around major transportation, I think it’s{transportation services}more political than some of the other resources that were established.” ~ *Navigator*

Navigators also voiced concerns about the lack of funding and payment for the work they do, as well as the lack of appreciation received from the practitioners. In relation to the patients, navigators conveyed their thoughts about setting boundaries and the ability to separate personal life from professional work. For instance, the relationships developed between the patients and navigators become so intertwined that patients sometimes ask navigators to assist them with non-health care related tasks. Thereby placing the navigator in an awkward position to establish role limitations.

> "…but sometime we also need to let them know that umm my responsibilities go to this limit and I cannot go beyond the limit. And if you set that from the beginning I think that they will respect, and they will really you know let you do your job easy umm don't let them, don't give the patient an illusion that you are their savior. " ~ *Navigator*

4.4.2 Patient-Physician Communication

4.4.2.a – Accurate Interpretation & Relay Information: Functional Tasks

Upon examining the impact of patient navigation services on patient-physician communication, many practitioners indicated that navigators were instrumental in providing accurate interpretations and relaying relevant cancer care information. Some physicians shared their encounters with patients' relatives (i.e. children) serving as interpreters and expressed their uneasiness with the degree of truthfulness of the information conveyed to the patients. Many physicians voiced positive views about the process by which navigators facilitated the two-way conversation and how their communication skills and professionalism contributed to improved follow-up visits and better health outcomes.

> "When these navigators come with the patients…from the same culture, background, so they can communicate, that culture and that {patient} did much better to us." ~ *Practitioner, OB/Gyn*

> "So some interpreters have a good understand of those medical terminology in their specific language and other people don't. Another thing is being able to interpret the question as closely as possible to what they physician is asking. One of my frustrations is always when I'm asking you know we're speaking and someone's translating and I know it's completely different from what I I'm saying. It can be very frustrating because that communication can be poor that way." ~ *Practitioner, Medical Oncologist*

> “It helps a lot in uh, uh, communicating. It makes me understand their problem better, and it helps communicate what I, how I want to do, to provide the care to them better.” ~ *Practitioner, Internal Medicine*

Practitioners also noticed that patients were more comfortable sharing their problems in the presence of navigators. This perception may be attributed to the fact that patients are able to maintain a higher degree of privacy, when sharing their health care questions and concerns, in the presence of navigators rather than family members. Patients were also less anxious because they had the opportunity to ask questions and share concerns, allowing them to be more engaged in the management of their health.

> “If I’m with a navigator, you know, {patient} may feel more comfortable to bring up, uh, problems and issues then when they come, when they come with a family member.” ~ *Practitioner, OB/Gyn*

From the navigators’ perspective, some stated that the physicians they worked with valued their skills and their opinions about the care provided to patients. This can be attributed to the navigator’s knowledge of the patient’s cultural background and their ability to relay information that would benefit the patient’s health and well-being. They also voiced the importance of conveying to physicians the value of the services, such that it goes beyond cultural knowledge or language skills, but more of a resource to facilitate communication and better health outcomes.

> “I think that they value, uh, good interpretation and translate everything that was going on, and maybe, like give them suggestion on cultural background, maybe, because, like, or, I think they also want to know whatever they make-, whatever treatment they taking beside the traditional treatment…like if the patient take any herbs or something they would like to know about that. “~ *Navigator*

> “I think in a way if we kind of make the doctors aware of that, that we are also there as a resource for them, and that patients, so that it’s a continuum of care, that it’s not just a one way referral and that’s all.” ~ *Navigator*

4.4.3 Evidence for Adoption & Integration

With regards to practitioner perspectives about incorporating PNPs into the current health care system, many agreed with the idea of making PNPs available at all health care facilities. However suggestions and thoughts about the logistics of adoption and integration of PNPs varied. Some physicians expressed concern about their ability to coordinate the implementation process due to time and resource constraints,

> "From the standpoint of putting that in place, uh, and organizing, initial should come from the legislation, and uh, government, more stable and stronger resources than the individual offices of the physician. So, in a nutshell, how I see it is the government should support these programs. People from the program should contact the physician and develop a network of the, uh, services." ~ *Practitioner, Medical Director*

Others believed that the sustainability of PNPs required a lot of effort, especially if funding resources are limited and if the interest and dedication of the patient navigators did not coincide with the need for such a program.

> "It would be good. Practical. But I mean, who's going to be paying for that? The issue is going to be coming up. " ~ *Practitioner, Family Practice*

> "You know, you train a group of people, lay educator, or lay navigator…you train 10 and you retain one maybe." ~ *Practitioner, Medical Oncologist*

The evidence needed for the incorporation and adoption of PNPs can also be found in the clinical experiences of health care practitioners and their perceptions of the value of having a navigator at their respective health care institutions. Some Practitioners expressed the utility of having a navigator who was not only familiar with the patient's cultural background and effectively communicates in English and the patient's language, but was also knowledgeable about the health care system,

> "{The navigator} has been a prime example of a real system that works very well. Much better than the health navigators here in our…in our own hospital for instance um I mean clearly the patient…the patient navigators here in our hospital are not trained translators (sic) and they're told that

> they're not supposed to provide translation services (sic). Well okay, that means they do a piece of it but what about the other piece (laugh). Where {the navigator} has really been able to do both pieces as a translation plus a navigator um…" ~ *Practitioner, Nurse Practitioner*
>
> "You know, all of those things, you don't have to keep repeating things, she knows our system by now, she kind of knows what the process is and she's… she's caught on easily and uh it makes it easy on all of us. "
> ~ *Practitioner, Nurse Practitioner*
>
> "…if the one or two trained interpreters are not available or not in the language you need, then our back-up plan is the Siracom translation line."
> ~ *Practitioner, Nurse Practitioner*

Although some health care institutions were equipped with a telephone interpretation system (i.e. Siracom), practitioners indicated that the presence of navigators during the appointments was more useful. The phone system allowed patients to communicate with their physicians, but navigators were more effective in providing practitioners with additional background information about the patients' cultural practices and beliefs in order to help them achieve better health outcomes. As reference, translation and interpretation skills are similar in the realm of linguistics. The difference between the two is that translation is associated with written text and involves the capacity to understand the source and culture of the language, while interpretation is associated with translating orally and involves the ability to "translate in both directions on the spot" with the aptitude to listen to one language and paraphrase in a culturally appropriate and informative way into another (Language Scientific, 2014).

4.5 – Discussion

Access to cancer care services can be a challenge to individuals unfamiliar with the U.S. health care system, but patient navigation services can serve as a mechanism to address this issue. Among SEAs, language and lack of education and knowledge about health care services have been barriers in obtaining health care (Ma et al., 2009; Shah et al., 2010). The general perception about the utility of patient navigators in addressing health care access issues appears to follow the pattern currently found in the literature, such that navigation services have been instrumental in reducing access barriers through effective means of communication and information exchange (Paskett, Harrop, & Wells, 2011; Pratt-Chapman, Simon, Patterson, Risendal, & Patierno, 2011).

The objective of this study was to understand PNPs from the perspective of practitioners and patient navigators, to examine the impact of patient navigation services on access to care, and to identify strategies for the adoption and integration of PNPs. Secondary analysis of interview transcripts revealed that health care practitioners found patient navigation services to be genuinely valuable in assisting SEA breast cancer patients access and receive cancer care services in a timely fashion. The data also brought to light the degree of time and effort it took for patient navigators to identify and coordinate breast health services for these immigrant ethnic groups. Although actual "time and effort" was not clearly quantified, some of the clinicians who worked closely with patient navigators were familiar with the barriers and challenges to obtaining care and the level of commitment the navigators had in assisting the breast cancer patients. A prime example would be the perspective shared by the Nurse Practitioner who expressed the existing gap in the system, such that patients requiring expensive medical tests are often referred to the county health care system, which involves time-consuming efforts to obtain necessary exams. A summary of the benefits of and challenges with PNPs is found in Table 4.2-Advantages & Benefits of PNPs.

Table 4.2 – Advantages & Barriers to PNPs

Advantages	Barriers
• Coordinated cancer care services • Increased rates of appointment attendance • Better understanding of disease & disease process • Improved patient-physician communication • Increased physician awareness of patient needs • Trust & adherence to recommended therapy	• Retention of navigators • Lack of availability at health care facilities • Practitioners' limited knowledge of PNPs • Lack of funding/Unpaid positions • Limited resources for patient navigators

Practitioner perceptions of PNPs expressed in this study highlight the need to inform cancer care clinicians and cancer care institutions about the value of patient navigation services. Although interviews were conducted with practitioners who had some exposure to patient navigators, analysis of the transcripts reveal that many were not aware of or familiar with the community agencies that offered patient navigation services. Others were also uninformed about the depth of assistance navigators provided. Most of the health care practitioners expressed their familiarity with the patient navigators and knew the navigators by name, but actual knowledge about PNPs and how they were established was limited. Results from this in-depth analysis present feedback from practitioners that is not currently available in the literature, such as lack of knowledge about PNPs and limited understanding about the range of services navigators have to offer. Stakeholders, like AANCART's outreach core, can utilize these findings to inform and educate health care practitioners about the range of services and garner support for the adoption and implementation of PNPs. AANCART can also serve as the organizational agent to link practitioners and health care facilities, especially for those agencies in areas who serve larger AA subgroups, to community agencies with existing PNPs.

The study findings suggest that the impact of patient navigation services on accessing cancer care services and improving patient-physician communication was beneficial, not only for patients, but equally so for the health care practitioners. Clinicians stated that navigators were instrumental in coordinating necessary treatment and follow-up care and making sure that patients were present for their appointments. Most of the patient navigators echoed this sentiment by outlining the techniques they used to get the women to their appointments and examinations. Some navigators expressed their pro-activeness, with regards to advanced scheduling of necessary follow-up care and thorough explanations of what to expect during the appointments.

As a center charged with reducing cancer health disparities, AANCART could document the methods and procedures used by navigators to access care for the women they serve. The information gathered could then be shared with community agencies with existing PNPs or those looking to provide patient navigation services, and could serve as a guide for new navigators or as an additional tool for veterans. For instance, some interviewed navigators expressed how they turn to more experienced navigators for assistance when helping patients in a difficult situation (e.g. obtaining necessary medications for patients with financial constraints).

4.5.1 Addressing Barriers – Patient-Physician Communication

Navigators were found to foster communication between the patients and practitioners by accurately relaying the fears and concerns patients had in accessing and adhering to follow-up care. Similarly, practitioners conveyed that navigators assisted them in gaining a better understanding about their patients' readiness to receive cancer care services and aided with discussions about treatment options that patients were more likely follow. The findings presented in this study allude to the need for an increase in the availability of patient navigation services and, notably, the decrease in reliance on untrained family members to serve as translators/interpreters. Practitioner and navigator interview transcripts showcased the limitations of using family members to relay information in the health care setting, such as the patients' inability to discuss intimacy issues when children serve as interpreters or inaccurate translations by family members with limited medical knowledge. They also highlighted the multitude of benefits (e.g. adherence to follow-up care and improved health outcomes) associated with PNPs. Stakeholders with a vested interest in reducing cancer care disparities and increasing the availability of patient navigation services can use the results generated from this study to advocate for resources to improve existing PNPs.

4.5.2 Knowledge of Program Implementation

While the data presented in this study supports the need for PNPs, clinicians were unclear about how navigators could be integrated and sustained in their agencies. Although some suggested turning to government agencies or legislation to increase the availability of patient navigation services, the majority of practitioners were unsure of the steps needed to incorporate PNPs at the systems level.

One suggestion would be to establish a national patient navigator certification program, which would enable insurance companies to reimburse navigators for their services. Although a patient navigation certification program does not exist, steps are being made to provide incentives for the support of coordinated care. Within the Patient Protection and Affordable Care Act (ACA), the Center for Medicare and Medicaid Innovation was created to "test innovative delivery and payment methods", such as Accountable Care Organizations (ACO) that was designed to "promote care coordination in a fragmented system" (George Washington Cancer Institute, 2013). Through ACOs, which is a voluntary program for health care providers that offers high quality care to Medicare patients, PNPs may serve as a tool to increase utilization of preventive services (i.e. recommended cancer screening tests) and foster recognition of the value of patient navigation services for all individuals, especially underserved, low-income, non-

English speaking or low health literacy, and immigrant populations (Centers for Medicare and Medicaid Services, 2014; George Washington Cancer Institute, 2013).

Additionally, both navigators and practitioners agreed that advocating for increased PNPs at the policy level is the best approach, yet they were unable to give suggestions as to who would step up for this leadership role. As a center focused on reducing health disparities, AANCART could work in partnership with Asian American and Pacific Islander organizations, like the Asian Pacific Islander American Health Forum (APIAHF) and the Association of Asian Pacific Community Health Organizations (AAPCHO), to formalize a collaborative campaign to draw more attention to existing PNPs, especially active programs within their network of community agencies. Using the data gathered from this study, they could highlight the positive aspects of patient navigation services and emphasize the need for this type of resource, while simultaneously generating discussion on approaches to reducing the barriers and challenges to adoption and integration and to improve cancer outcomes specifically, particularly for monolingual, limited English proficient, low-income SEA clients and families.

4.6 – Appendices

Appendix 4.1 – Interview Guide: Providers

8/29/07

INTERVIEW GUIDE
PROVIDERS

1. What is your title and area of medical expertise?

2. How long have you worked with patients from the Southeast Asian communities?

3. Do you speak languages other than English? What do you do when you have a non-English speaking or limited English proficient (LEP) patient?

4. Have you heard about community-based health navigators? How would you define a community-based health navigator? What are your general thoughts about the services provided by community-based health navigators?

5. How often do your patients come in with health navigators? What proportion of your Southeast Asian patients come in with health navigators?

6. How are your Southeast Asian patient encounters with a navigator generally different from those without a navigator?

7. How has patient navigation services affected communication between you and your patients?

8. How does having a health navigator affect your understanding of your patients' health needs?

9. How does having a health navigator affect your understanding of your patients' cultural background and how this might influence her health care experience?

10. How do you think health navigation services affect your patients' readiness and ability to obtain screening and/or treatment services?

11. How do you think having a health navigator affects your patients' understanding of suggested follow-up care or treatment options?

12. What aspects of health navigation do you believe are especially needed to support a patient through the cancer care continuum – from screening through diagnosis, treatment, and recovery?

13. What other important functions do navigators serve for your patients? For you?

14. What qualities or characteristics do you value or like to see in a health navigator?

15. What areas or kinds of training do you think all community-based breast cancer health navigators should receive? What kinds of information and skills should all health navigators have?

16. What are some negative aspects of having health navigators or health navigation in general?

17. What would you change, if anything, about the navigation services provided to your Southeast Asian patients?

18. What are your thoughts about incorporating patient navigation services into the health care system? How do you think this should be done?

19. Do you have any other comments you would like to add?

Ask provider to fill out checklist of training curriculum topic areas

Appendix 4.2 – Interview Guide: Navigators

INTERVIEW GUIDE
NAVIGATORS

1. What services do you provide as a community-based patient health navigator?

2. When I interviewed you several years ago at the beginning of the PATH for Women program, you mentioned the following strategies that helped you to outreach to and educate women {SPECIFIC LIST AND QUOTES FOR EACH NAVIGATOR}.

   In the four years since that time and looking at your experience with navigating women for the PATH for Women program, what have you found to be the most effective strategies to motivate women in your community to obtain breast health screening and follow-up services?

3. What have you found to be the best ways to establish trust, credibility, and respect with the women you work with in the community?

4. As a health navigator, what do you think are the most important services you provide to help women in your community access breast health care services?

5. Please tell me what you think women expect of you as you navigate them through the health care system?

6. Are there any typical scenarios or common problems that you've seen women go through for breast cancer screening, diagnosis, treatment, and survivor support services? How do you address these issues?

7. What qualities or characteristics do you think patients value or like to see for a health navigator? What qualities or characteristics do you think doctors value or like to see for a health navigator?
8. What areas or kinds of training do you think all community-based breast cancer health navigators should receive? What kinds of information and skills should all health navigators have?
9. What are some negative aspects about being a health navigator or about health navigation in general?
10. What would you change, if anything, about the navigation services you have provided to your clients?

11. What are your thoughts about incorporating health navigation services into the health care system? How do you think this should be done?

12. Knowing what you know now, are there topic areas or skills you wish you could have gotten training for as a health navigator that you did not receive?

13. Do you have any other comments you would like to add?

Ask navigator to fill out checklist of training curriculum topic areas

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CHAPTER 5

Conclusion of Dissertation Findings

5.1 – Overview

This dissertation studied the influence of a policy, the Patient Navigation Outreach and Chronic Disease Prevention Act (NOA), on the availability of patient navigation programs (PNPs) and the role of navigation services in improving quality of care for Southeast Asian (SEA) breast cancer patients in Los Angeles (LA) and Orange counties (OC). The study employed surveys, tumor registry data, and interview transcripts to conduct two studies examining: 1) whether a legislative act improved the availability of PNPs and if navigation services contributed to the timely receipt of breast cancer treatments, and 2) whether the perspectives of health care practitioners conveyed the evidence needed to support the adoption and integration of PNPs into the U.S. health care system.

This chapter summarizes the findings from the above two studies and discusses the limitations and strengths of the research. This chapter also highlights the importance of the study results for organizations that work with SEA communities and provides recommendations for the Asian American Network for Cancer Awareness, Research, and Training (AANCART) outreach core about actions to improve access and quality of care for Asian American (AA) women with breast cancer. The chapter concludes with a discussion of future research and policy implications related to PNPs and cancer care services for underserved AA populations.

5.1.1 Patient Navigation Programs and Breast Cancer Treatments

In health care delivery systems, patient navigation appears to still be a fairly new concept and not all health care providers are familiar with the terminology. Of the 24 institutions identified through the tumor registry and web-based search, only seven had established PNPs to assist patients diagnosed with breast cancer. Policy analysis indicated that of these seven hospitals, a total of four enacted PNPs during the Post-NOA funding period (2006-2010), two developed PNPs after the NOA funding period (2011-2012), and one facility developed a program during the pre-NOA period (2000-2005) but was excluded from analysis since it did not meet the study definition of PNP availability. None of the PNPs identified for this study was funded through the mechanisms established by the NOA.

Findings from Study 1, “Legislation Effect on Quality of Care,” revealed that enactment of the NOA was not associated with the development of PNPs in facilities in LA or OC. Survey responses further indicate that compliance with certification requirements, such as the Commission on Cancer-Cancer Programs Standards 2012 (CoC) established by the American College of Surgeons (ACOS), was one of the forces behind the creation of PNPs at facilities with (PNP-available) and without (PNP-unavailable) patient navigation services. According to the CoC standard on patient navigation services, health care institutions seeking CoC accreditation must phase in a PNP by 2015, and compliance requires that institutions: 1) conduct a needs assessment to address health care disparities, 2) establish a PNP, 3) conduct an annual assessment on barriers to care, and 4) modify/enhance PNPs annual to address barriers to care (American College of Surgeons, 2012).

Similarly, another factor that may have contributed to the development of PNPs may be due to mandates under the National Standards for Culturally and Linguistically Appropriate Services (National CLAS Standards). Through the National CLAS standards, Standards 4-7 (education/training of leaders, information and availability of language assistance, and competency of language providers) are federal requirements for all institutions receiving federal funds and facilities seeking accreditation through The Joint Commission (Office of Minority Health, 2013). Therefore, any facility that may have applied for and received federal funds or institutions with programs, such as PNPs, that incorporate a cultural competency aspect, will need to meet these certification requirements.

Development of PNPs in facilities that did not indicate “certification requirements” as a reason for establishing navigation services may be due to spill-over effects associated with the variety of organizations (e.g. American Cancer Society, AVON Foundation, etc.) providing demonstration grants for the creation of PNPs or due to efforts at addressing health care disparities. Therefore, the NOA may have served to mediate guidelines set by professional organizations.

With regards to whether the NOA contributed to the timely receipt of treatment after diagnosis, findings indicate that there was no association between enactment of the NOA and the availability of PNPs. Results also show that the proportion of patients who received surgery within 30 days was higher at pre-NOA period at both PNP-available and PNP-unavailable facilities. Analysis of median time to surgery after diagnosis showed that regardless of the availability of PNPs, women took more time to obtain surgery in the post-NOA period compared to the pre-NOA period. These results could be associated with treatment guidelines that facilities may have followed during the pre-NOA period (2000-2005). Another reason for lower proportions at post-NOA may be associated with proactive patients seeking second opinions or choosing neoadjuvant therapies rather than immediately opting for surgery.

Looking at ethnic group differences, Study 1 findings show that more SEAs, compared to Hispanics and non-Hispanic whites (NHWs), received surgery within 30 days at both time periods in PNP-available facilities, however numbers of SEAs were too small to make definitive conclusions, and may have skewed the data in favor of SEAs.

5.2 – Practitioner and Navigator Perceptions of PNPs

Publications assessing PNPs have generally focused on the perception of patients who received navigation services and a few studies have investigated the perspectives of navigators. Rarely has the views and opinions of practitioners about PNPs been explored. Findings from Study 1 and Study 2, "Practitioner Perceptions of Patient Navigation Programs", were reviewed and responses to the Facility Survey were similar to those gathered from the interviews with health care providers and navigators. The reactions of providers and navigators concurred with one another, especially in regards to highlighting the barriers and challenges for the adoption and integration of PNPs.

5.2.1 Practitioner Perspectives

Practitioner perceptions are drawn mainly from the interview transcripts, yet their opinions pertaining to the context, facilitation and evidence about the implementation of PNPs matched the responses generated from the Facility Survey that was administered in the first study. Clinical knowledge about the process for establishing a PNP was limited, yet the little information practitioners were able to share, based on their experience with navigators, suggests that they are aware of the value of PNPs and the services rendered by navigators. For instance, interviews with practitioners emphasized their appreciation for the navigators' skills and abilities when relaying the importance of obtaining cancer care services, facilitating communication, and helping SEAs patients get to necessary appointments. Coincidentally, Facility Survey responses indicate that among the list of services provided by navigators, education, scheduling, access to treatments/post-treatments and counseling were among the most frequently noted. Cross referencing these findings alludes to the possibility that health care practitioners are not fully aware of the range of services PNPs provide. Thereby suggesting that PNPs are relatively new to clinicians and that additional outreach is needed to highlight the utility of navigators in order to garner support for the integration of PNPs at the system level.

In terms of the facilitation of PNPs, practitioner interviews indicated that they were unaware of how navigation services were established or made available, but they did understand the limitations of such programs. For instance, interviews indicated that clinicians discussed the need for funding to make navigation services more widely available, since the accessibility of navigators was limited to select facilities and for certain ethnic groups. Similarly, survey respondents highlighted “lack of financial resources” and “insufficient staff” as primary barriers to the facilitation of PNPs, which suggests issues associated with sustainability of PNPs.

In general, interviews with practitioners highlighted the importance of patient-physician communication and the role that navigators had in addressing this concern. Navigators were instrumental in helping patients understand the disease and treatment process better, which then enabled patients to be more engaged in conversations with their physicians. Practitioners also noticed that with the aide of navigators, patients had a better understanding of the importance of adherence to treatment regimens. Due to language barriers and time constraints, practitioners are unable to relay important aspects of cancer therapies to SEA patients, but many of the clinicians observed that patients who spent time with the patient navigators were more comfortable and receptive to the information they shared during office visits.

With regards to perspectives about the integration and adoption of PNPs, providers expressed their support for the system level inclusion of these programs but lacked the knowledge and understanding of how to proceed with implementation. The clinicians expressed that the first step for the integration of PNPs should stem from legislation and government organizations equipped with resources to follow through with the process. This implies that future research should investigate the processes with which existing PNPs were established and to identify the guidelines and protocols that may have been used by facilities to provide navigation services to target communities.

5.2.2 Navigator Perspectives

Similar to practitioner assessments, interviews with navigators coincided with the responses collected from the surveys about the type of services provided by navigators, and the challenges of developing and maintaining PNPs. As previously stated, education of and scheduling for appointments were important elements of navigation programs, and lack of funding and staffing were barriers. However, a key element emphasized by the navigators in the interviews was their understanding of the importance in helping patients become more knowledgeable about the health care system and to become self-advocates. Navigators understood the balance of helping patients at every step of the process, but also educating them on what they need to do to access health care services and how to be self-sufficient. This finding not only points to the value of navigators in assisting patients, but the complexity of the U.S. health care system when trying to access cancer care services.

5.3 – Recommendations for AANCART

Recommendation 1: Investigate the availability of PNPs for Asian Americans

The study findings point to the limited availability of PNPs in health care facilities serving SEAs and inadequate resources that are actually tailored for or target AA subgroups. A two-step process for addressing this dilemma would be to: 1) assess where navigation services exist (e.g. hospitals or community agencies), what ethnic groups they cater to, and how navigation services are implemented and supported, and then 2) disseminate this collective information about PNPs to AANCART partners. These actions would equip organizations, which already target SEAs and diverse AA subgroups, with the knowledge and resources needed to improve access to cancer care services and reduce delays in the receipt of treatments. Additionally, identification of existing PNPs would reduce program duplication efforts by institutions and organizations looking to establish navigation services in areas that already provide such services. Therefore, resources aimed at developing new PNPs can be more efficiently used to support existing programs and identify mechanisms for sustainability and program enhancements, as well as the development of new resources building on the experience of the established programs.

Recommendation 2: Inform clinicians and health care institutions about the importance and utility of patient navigation services

Responses from the provider interviews in Study 2 indicate that very few clinicians are familiar with PNPs and the role that navigators play for both health care practitioners and patients. Since PNPs are not readily available at all health care facilities that serve SEA breast cancer patients and because navigators who actually work with SEAs in this data set are based at community agencies rather than hospitals, efforts to outreach to cancer care facilities and bring awareness of established PNPs would benefit both clinicians and patients. Knowledge of PNPs or how to access patient navigation services would enable providers, especially those who serve SEA patients, to obtain the services and assistance they need to better communicate with patients and provide them with necessary health care resources. Clinicians can also refer patients to institutions and community agencies that offer navigation services as a way to help them seek guidance and additional information about proper actions for obtaining cancer care services. More importantly, awareness of navigation services would essentially reduce the reliance on family members to serve as interpreters during office visits and possibly result in more efficient and effective conversations with clinicians and adherence to treatments.

Recommendation 3: Establish educational forums or seminars that enhance the skills of existing patient navigators

Interview responses from providers in study 2 indicated that knowledge about the U.S. health care system is a skill they believe would be an instrumental tool for patient navigators. Findings from Study 1 also allude to the utility of seminars as a source of training for navigators, such as updates on breast health services, modifications to the health care system (i.e. regulations associated with public insurance) or techniques for navigating patients. Familiarity with cancer care services and resources is an important aspect, but awareness of how the current health care system functions and how to access services for breast cancer patients constrained by low-income, immigration status, or lack of health insurance coverage are essential to reducing disparities in quality of care. Experienced navigators may have acquired the knowledge to avoid systemic barriers through trial and error, but the health care system is constantly changing, especially with the enactment of the Affordable Care Act. Existing navigators would benefit from seminars that highlight changes to the current system and new navigators may gain from the knowledge and advice of experienced navigators.

Recommendation 4: Identify funding sources

As indicated in both studies, lack of financial resources is a major obstacle to the capacity building efforts and sustainability of PNPs. Although PNP-available facilities were able to establish PNPs, a policy review of the NOA indicated that appropriations were not made to any of the LA and OC facilities. Thus, enacting legislation with funding is not enough to encourage facilities to implement PNPs.

According to Study 1, existing navigators at PNP-available facilities are paid by the hospital, which receive funding through foundations and donations. However, most of the PNP-available facilities employ no more than two navigators and these individuals are often overwhelmed and overextended by the workload. Identifying mechanisms to financially support navigators and expand existing PNPs, especially those based at community organizations, is needed to improve health care access for underserved SEA breast cancer patients, and other ethnic groups with similar demographic characteristics. One option would be to assess how financial support through foundations and donations is garnered by hospital-based PNPs. A second option would be to partner with hospital-based PNPs and develop a mechanism to utilize community-based navigators and pay them per diem. Most importantly, another option would be to conduct the studies needed to establish the clinical and cost-effectiveness of PNPs and to produce the evidence needed to enable PNP advocates to build the argument to develop policy requirements for patient navigators to be paid through health insurance.

5.4 – Limitations

There are a few quantitative and qualitative limitations that should be acknowledged in the research.

5.4.1 Study 1 – Quantitative

Study 1 involved contacting the 24 facilities in the LA and OC areas that serve SEA breast cancer patients and have PNPs. A total of 20 facilities were identified by the tumor registry as serving at least 2-3% of SEA women, however, since only two were confirmed as having PNPs, there was insufficient data for facility comparison. Therefore, facilities identified through the web-based search as having PNPs were contacted in order to confirm the availability of PNPs and to obtain sufficient descriptive data (i.e. completion of the Facility Survey) for comparison. This process generated an additional three hospitals confirmed as having a PNP, but only two met the study criteria of establishing PNPs during the post-NOA time period (2006-2010) and were included in the study analysis.

Since “patient-centered care programs” or “patient navigation programs” are uncommon terminologies, the ability to identify a contact person at each facility with knowledge about PNPs was challenging. If key personnel were identified, actual contact required multiple attempts to set-up the initial phone conversation to administer the Short Telephone Questionnaire, which was coupled with scheduling conflicts. Therefore, confirming the availability of PNPs resulted in actual contact with a little more than half (n=14) of the hospitals listed during a span of four months. Additional time to identify key personnel may not have garnered any additional confirmations of PNPs since the terminology to distinguish patient navigation services or programs targeting breast cancer patients is different at each facility.

Analysis involved a combination of data sources: survey responses and tumor registry data. Information gathered from the surveys was limited to descriptive information. Since tumor registry data was not directly requested from the regional cancer registry, data analysis was restricted to data requests that examined aggregate data of the target populations rather than individual patient cases. Additionally, analyses of specific patient cases for each health care facility was limited since permissions to review tumor registry data were not granted by all of the contacted institutions. Also, patients were not directly contacted to assess and confirm their use of PNPs. Thus, by using geographic data as a proxy for facility permissions, assumptions were made that patients obtained services from the facility that was within the 1-mile vicinity of their residence.

Statistical review of tumor registry data did not involve multivariate analyses, but was limited to frequency distributions, medians and cross-tabs. The receipt of permission from only two facilities and the use of geographic catchment areas, as opposed to actual case listings from the 14 hospitals contacted, and the generalizability of the results pertaining to timely receipt of treatment options was limited by the lack of direct confirmation from patients about the use of PNPs.

5.4.2 Study 2 – Qualitative

Study 2 involved secondary analyses of interview transcripts with providers and navigators. Data gathered about PNPs from the transcripts was limited by the questions asked during the implementation of the original study. The type of respondent (i.e. clinical position/title of health care provider) and background information about the interviewed study participants was also restricted to the questions asked during the original study, since this information was not part of the dataset. A few of the transcripts included un-translated terms and sentences (i.e. responses were in Vietnamese), so any information about PNPs within these transcripts were not usable. Additionally, if responses were unclear in the transcripts, the study researcher could not refer back to audio files to verify the information.

5.5 – Implications for Future Research

Results from these two studies showed that a legislative policy was not associated with the availability of PNPs in LA and OC facilities serving a high proportion of SEA breast cancer patients. The policy was also not associated with timely receipt of surgical treatments. However other patient centered outcome measures should be considered to evaluate the effectiveness of PNPs. Legislation may have indirectly contributed to the awareness and the value of establishing PNPs. Additional research is needed to identify factors that motivated the development of PNPs among facilities that established navigation services during the post-NOA period. Information, such as institutional guidelines or accreditation requirements, would be useful in understanding the circumstances that contributed to establishment of these programs, as well as the processes program leaders followed to successfully implement a PNP. If legislation was a primary factor, then efforts to support local or regional policies that advocate for patient-centered programs should be encouraged. Conversely, research to determine the lack of interest in PNPs at facilities that do not have a navigation program would be useful in determining the type of elements that should be in place before developing a PNP program. For instance, questions that should be considered are: 1) Does the health care institution identify a need for patient navigation services, 2) Are there identified leaders willing to support the program, 3) How would the target population benefit from the program? Assessing the needs and wants of a health care facility may explain why some programs are successful and others are not.

With regards to the usefulness of patient navigators in accessing cancer care services and the timely receipt of cancer treatments, greater in-depth research to directly assess the use of PNPs is necessary to fully understand the role of navigators, if any, in reducing delays between diagnosis and completion of treatment. Data collected from this type of research could possibly showcase the cost-effectiveness of PNPs and garner the support needed to integrate navigation services at the system level.

5.6– Conclusion

The U.S. health care system is a complex network that requires a substantial amount of knowledge and understanding and assertiveness in order to be used effectively. In the last 15 years, patient navigation programs have evolved into a mechanism for assisting communities with the greatest health care needs, yet it remains a fairly new tool in improving timely receipt of care and reducing cancer care disparities. Study findings suggest that patient navigator programs are slowly being developed and the utility of the services provided, from the perspective of clinicians as well as patients, is gradually being recognized. Future research should focus on legislative and organizational strategies to increase support for the establishment and implementation of patient navigator programs, particularly in areas that serve communities with the highest cancer care disparities.

5.7 – References

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