

DISSERTATION

DELAY TO TREATMENT FOR LATINOS DIAGNOSED WITH LUNG AND HEAD-AND-  
NECK CANCERS: APPLICATION OF THE BEHAVIORAL MODEL FOR VULNERABLE  
POPULATIONS

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## ABSTRACT

### DELAY TO TREATMENT FOR LATINOS DIAGNOSED WITH LUNG AND HEAD-AND-NECK CANCERS: APPLICATION OF THE BEHAVIORAL MODEL FOR VULNERABLE POPULATIONS

Since the enactment of the National Cancer Act of 1971, many Americans have seen improved rates of survival from cancer. However, this is not true of all ethnic groups, and Latino cancer patients in particular tend to have poorer survival rates than those from other ethnic groups. The timely and appropriate treatment of lung and head-and-neck cancers is an especially serious matter because of the relative complexity of these cancers as well as the high mortality risks associated with them. This study applied a well-known theoretical model of health care access and utilization, the Behavioral Model for Vulnerable Populations, to examine factors related to time from diagnosis to first treatment for Latino patients diagnosed with lung and head-and-neck cancers. Using a mixed method design, medical chart reviews were conducted on 53 Latinos diagnosed with lung or head-and-neck cancer, and interviews and focus groups were conducted with five Latino head-and-neck and four lung cancer patients, six caregivers, seven key informants, and seven patient navigators. A model including predisposing (age, gender, country of origin, and language), enabling (insurance status and regular dwelling), and need factors (site of cancer, stage of cancer at diagnosis and number of co-occurring illnesses) accounted for 32% of the variance in time from diagnosis to first treatment. Number of co-occurring illnesses was the only significant predictive factor, demonstrating that with each additional comorbid condition, delay from diagnosis to treatment decreased by 18.72 days. An interaction between number of comorbid conditions and gender revealed that females with a low number of co-occurring illnesses tend to experience the longest delays from diagnosis until

treatment. The qualitative data provided support for the influence of predisposing, enabling, and need factors as well as suggested several additional factors that were not analyzed through the medical chart reviews. These additional factors may account for a portion of the remaining variance in time from diagnosis to treatment. This study underscores the need for continued efforts to examine and consider these factors and to utilize them to work to ameliorate delays in time to treatment.

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## Literature Review

### Cancer and Medically Underserved Populations

The National Cancer Act of 1971 has greatly improved our understanding of the causes, prevention, detection, and treatment of cancer. However, all Americans have not experienced the benefits, including increased survival rates. Those in underserved populations specifically have not appeared to benefit equally. Evidence of this disparity is seen throughout the literature as ethnic minorities, including Latinos, diagnosed with cancer have both less favorable presentations and outcomes. It has been asserted that the lower survival rates experienced by low-income Latinos are not solely due to their advanced cancer stages at diagnosis (Clegg, Li, Hankey, Chu, & Edwards, 2002; Shavers, Harlan, & Stevens, 2003; Biffl, Myers, Francoise, Gonzalez, & Darnell, 2001). Instead, it has been shown that the treatment journey experienced by Latinos is more hazardous as they are more likely to be lost at follow-up after receiving abnormal cancer screening results, have longer delays between diagnosis and treatment, and are less likely to follow recommendations for treatment (Colorado Cancer Coalition, CCC, 2005). Latinos in particular are less likely to receive chemotherapy and surgical resection for certain types of cancer than their non-Latino/a counterparts (Fry, Menck, & Winchester, 1996; Shavers & Brown, 2002).

Evidence exists that suggests delay in the diagnosis and treatment of cancer impacts both survival and survivorship outcomes (Elmore, Nakano, Linden, Reisch, Ayanian & Larson, 2005). Numerous explanations have been proposed for why this delay exists. Foremost among them is the idea that Latinos experience barriers in access to medical treatment. Barriers in access to care may influence time to diagnosis and/or treatment, which may therefore influence prognosis following a cancer diagnosis (Porter, Inglis, Wood & Veugelers, 2005). As previously found, the

barriers in access to care for Latinos diagnosed with lung and head-and-neck cancers include mental health factors (e.g., substance abuse and depression), socio-cultural factors (e.g., emotional protection of family and traditional health practices), medical factors (e.g., health competency and adherence to treatment), and financial factors (e.g., insurance status and immigration status) (Scott, 2010).

The access barriers encountered by Latinos are similar to those mentioned in other studies examining barriers in access to care among underserved populations. The influence of socioeconomic status and insurance status on access to healthcare is well documented (Institute of Medicine, 2002). As shown in the literature, lower socioeconomic status negatively influences access to adequate healthcare and is associated with poorer outcomes (Cornelius, Smith & Simpson, 2002; Siminoff & Ross, 2005; Singh, Miller, Hankey & Edwards, 2004). The literature has also suggested that ethnic minorities receive poorer healthcare and that discrimination in delivery of care within our healthcare system leads to unequal health outcomes for ethnic minorities (Anderson, Yip, Ramsey et al., 2006; Institute of Medicine, 2008). Additionally, cultural factors have been shown to influence disparities in access to healthcare (Institute of Medicine, 2002; Betancourt & Maina, 2004; Ashing-Giwa, Padilla, Tejero & Kagawa-Singer, 2003). Limited English skills have been found to lead to difficulties in communication between patients and their healthcare providers. Furthermore, providing culturally competent care may be made difficult by lack of diversity training for healthcare providers (Institute of Medicine, 2002; Betancourt & Maina, 2004).

In addition to individual level factors, system factors may influence access to care for ethnic minorities. We have found that for Latinos diagnosed with lung and head-and-neck cancers, these system factors include the complexity of the hospital system structure and the

process of enrollment in resources (Carey, 2010). Other studies have shown that facility capacity and physician behavior may influence delays in healthcare (Ramos, Esteva, Cabeza, Campillo, Llobera & Aguilo, 2007; Langenbach, Schmidt, Neumann & Zirngibl, 2003).

These concerning trends in the treatment of cancer in ethnic minorities are especially relevant for Latinos diagnosed with lung and head-and-neck cancers. Although these types of cancers are relatively rare (approximately three-percent) among both Latinos and non-Latinos, the mortality rates of these types of cancers are particularly high (American Cancer Society, ACS, 2005). Additionally, the already high mortality rates are increasing rapidly for Latinos in Colorado as the rates rose 38% between 1997 and 2002 (Finch, Vu, & Karp, 2005). These trends are even more complex for lung and head-and-neck cancers as their treatment is especially complicated. For instance, the treatment of these types of cancer is often coordinated between Pulmonary Medicine, Medical Oncology, Surgery, ENT, and Radiation Oncology with additional support from Dietetics, Speech Therapy, and other divisions. Because of the involvement of all these divisions in the treatment process, it is important for patients diagnosed with lung and head-and-neck cancers to consult with various health care providers prior to beginning and during the course of a treatment plan.

The complexity and morbidity of lung and head-and-neck cancer coupled with the high mortality rate associated with these types of cancers may lead to significant psychological stress in addition to the physical effects of the disease. For instance, close to 50% of patients diagnosed with head-and-neck cancers show depressive symptoms during their treatment (Duffy et al., 2007). These patients may be at a higher risk for depression following their diagnosis as they are experiencing the threat and stress of cancer in addition to the difficult morbidity often seen during the course of this type of cancer (Katz, Irish, Devins, Rodin, & Gullane, 2000, 2003).

Head-and-neck cancer patients have described their experience as “catastrophic,” and often view the disease as an attack on the sense of self (Turpin et al., 2009). Depression, combined with pain and suffering, an array of physical symptoms, and advanced cancer staging (among other factors) can contribute to suicidality in cancer patients (Breitbart, 1994). Additionally, head-and-neck cancer patients may be predisposed for depression due to pre-morbid unhealthy coping habits, such as drinking and smoking. Research also indicates that patients diagnosed with lung and head-and-neck cancers are the most psychologically distressed sub-groups of cancer patients (Carlson et al., 2004; Zabora et al., 2001; Koster & Bergsma, 1990).

In addition to depression, a substantial number of lung cancer patients experience anxiety, which appears to increase as physical functioning decreases and patients experience more physical symptoms (Buchanan, Milroy, Baker, Thompson, & Levack, 2010; Hopwood & Stephens, 2000). Anxiety is also common in head-and-neck cancer patients, and fear of recurrence may be an especially salient concern for patients with these cancers because of their high recurrence rates (Hodges & Humprhis, 2009). Fear of cancer or its treatment has also been found to be prevalent among Latino/a head-and-neck and lung cancer patients and may even prevent some patients from receiving adequate treatment (Scott, 2010).

This psychological stress may also be impacted by the traumatic nature of lung and head-and-neck cancers. Patients with a diagnosis of lung and/or head-and-neck cancer may experience disruptions in various basic functions, such as breathing, swallowing, sight, smell, taste, and/or speech (McLane et al., 2003; Pandey et al., 2007). Cancer patients frequently experience additional symptoms such as fatigue, and many have disturbed sleep patterns (Liangi & AncoliIsrael, 2008). One of the symptoms most feared by cancer patients is pain, and evidence suggests that the prevalence of pain among this population is over 50% (van den Beuken-van

Everdingen, de Rijke, Kessels, Schouten, Kleef, & Patijn, 2007). The prevalence of pain is highest in head-and-neck cancer patients, with approximately 70% reporting significant pain symptoms (van den Beuken-van Everdingen et al., 2007). Surgical treatment procedures, especially for head-and-neck cancers, may also lead to physical disfigurement and/or dysfunction. The physical disfigurement associated with head-and-neck cancers in particular can have negative effects on patients' satisfaction with their appearance and overall self-esteem (Clarke, 1999; Liu, 2008). The potential long-term dysfunction and disfigurement experienced by these patients may also exacerbate emotional distress through difficulties with communication and emotional expression, social withdrawal, isolation, and sexual problems (Katz, Kopek, Waldron, Devins, & Tomlinson, 2004; Watt-Watson & Graydon, 1995). These patients may also experience stigmatization as individuals may assume they are at "fault" for their illness because of drinking and smoking behaviors and the patients may be confronted with negative behavior from others, such as staring, rude comments, and avoidance (Clarke, 1999; Gamba et al., 1992; Strauss, 1989).

Patients diagnosed with lung and head-and-neck cancers also tend to come from lower socio-economic backgrounds and thus tend to have access to fewer resources (Breitbart & Holland, 1988). Additionally, a vast majority (approximately 75%) of patients diagnosed with lung and head-and-neck cancers have a substance use history, thus causing them to face the added difficulty of ending their tobacco and alcohol use following their diagnosis. Given the multiple economic, medical, and mental stressors, these patients suffer from increased levels of psychological distress and are more likely to commit suicide in comparison to other cancer patients (Hammerlid, Silander, Hornestam, & Sullivan, 2001; Breitbart, 1994).

## **Behavioral Model for Vulnerable Populations**

Given the significant impact delay of treatment may have on survival and survivorship as well as the complicated treatment journeys experienced by Latinos diagnosed with lung and head-and-neck cancers, it is important to understand the method by which these patients experience delays in time to treatment. In order to elucidate this method, the Behavioral Model for Vulnerable Populations (Gelberg, Andersen, & Leake, 2000) was utilized, which developed from Andersen's Behavioral Model of Health Services Use (Andersen, 1968; Andersen & Newman, 1973; Andersen, 1995). This model has been used to examine health service use among vulnerable populations, including the elderly (Bass, Looman, and Ehrlich 1992; Wolinsky, Johnson, and Fitzgerald 1992), the homeless and those with HIV/AIDS (Gelberg et al. 2000), and children and adolescents with disabilities (Weller, Minkovitz, and Anderson 2003). Additionally, this model has been used to examine factors associated with dental services (Andersen and Davidson 1997), mental health services (Portes, Kyle, and Eaton 1992), and physical health services (Coughlin, Long, and Kendall 2002; Coulton and Frost 1982; Gelberg et al. 2000; Thind and Andersen 2003; Weller et al. 2003; Wolinsky 1978). The present study used the Behavioral Model of Health Services Use as a theoretical framework to examine factors that determine the use of cancer treatment services for a specific group: Latinos diagnosed with lung and head-and-neck cancers.

According to this model, health care utilization is a result of a pattern of interactions among three types of factors: predisposing, enabling, and need. Further, these factors have individual, systematic, and societal components. Predisposing factors are characteristics an individual has at the onset of their illness and describe their propensity to use health care services. This factor includes individual characteristics (e.g., gender, marital status, and age),

social structure characteristics (e.g., social class, education, race, and ethnicity), and health beliefs (e.g., value of health services, attitudes toward health services and physician use, and knowledge of the health care system). Social structure, particularly social class, influences the value individuals place on health and their perceptions of seeking care. Health beliefs are important in understanding the knowledge people have about the health care system and may also provide some understanding of why a person uses health services. This model asserts that an individual's predisposition to seek medical attention is a function of these aforementioned socio-demographic characteristics. However, these factors alone are not sufficient in explaining the method by which individuals use health care services. Enabling resources must be present for an individual to take advantage of medical services, and any use of medical care is influenced by how individuals view their own health status and their need for care.

Enabling resources of this model include the resources an individual has available to access specific services. Individual-level enabling resources must be present for an individual to use healthcare services. For instance, financial means, health insurance, a regular source of care, and place of residence are important enabling factors. Means of transportation and travel and wait time for health care services are also individual-level enabling factors. At the societal level, per capita community income, affluence, the rate of health insurance coverage, the relative price of goods and services, methods of compensating providers, and health care expenditures are considered enabling factors. Systemic enabling factors include the amount, varieties, locations, structures and distribution of health services facilities and personnel. It also involves physician-to-patient ratios, hospital density, physician office hours, and outreach and education programs. Health policies also fall into the category of contextual enabling factors.

Need characteristics are also important to consider in examining use of medical care. The Behavioral Model differentiates between perceived need for health services and evaluated need. Perceived need is an individual's perception that they have an illness, which is measured by symptoms an individual experiences, an individual's self-reported health status, or side effects of medical conditions and procedures. Evaluated need is measured by the actual medical problems they have been diagnosed with by health practitioners. Without a perceived or evaluated need for health care, it is unlikely that a person will use health care services. At the contextual level, environmental need includes the health-related conditions of the environment, such as occupational-, traffic-, and crime-related injury and death rates. Population health indices are overall measures of community health, including epidemiological indicators of mortality, morbidity, and disability.

### **Purpose**

The purpose of the current study is to better understand the factors impacting time to treatment for Latinos diagnosed with lung and head-and-neck cancers. The literature suggests factors unique to Latinos may be related to the delay to treatment they experience, but no research specifically examining this relationship exists. This study examined these factors, which can lead to recommendations to improve the treatment experience of these patients.

### **Hypotheses and Research Questions**

Hypothesis 1: Predisposing variables, such as age, gender, country of origin, and language, will have a *significant influence* on number of days from diagnosis of cancer to first treatment for Latinos diagnosed with lung and head-and-neck cancers.

Hypothesis 2: Enabling variables, such as insurance status and regular dwelling, will have a *significant influence* on number of days from diagnosis of cancer to first treatment for Latinos diagnosed with lung and head-and-neck cancers.

Hypothesis 3: Need variables, such as site of cancer, stage of cancer at diagnosis and number of co-occurring illnesses, will have a *significant influence* on number of days from diagnosis of cancer to first treatment for Latinos diagnosed with lung and head-and-neck cancers.

Research Question 1: What *predisposing factors* do patients, caregivers, providers, and patient navigators identify as influential on time from diagnosis to treatment for Latinos diagnosed with lung and head-and-neck cancers?

Research Question 2: What *enabling factors* do patients, caregivers, providers, and patient navigators identify as influential on time from diagnosis to treatment for Latinos diagnosed with lung and head-and-neck cancers?

Research Question 3: What *need factors* do patients, caregivers, providers, and patient navigators identify as influential on time from diagnosis to treatment for Latinos diagnosed with lung and head-and-neck cancers?

Research Question 4: What *additional factors* do patients, caregivers, providers, and patient navigators identify as influential on time from diagnosis to treatment for Latinos diagnosed with lung and head-and-neck cancers?

## **Method**

### **Study Design**

In this study, a mixed-method design was utilized to obtain a more comprehensive understanding of the factors that influence patients' use of health services to initiate cancer treatment. According to Tashakkori and Creswell (2008), mixing methods has served to satisfy

two purposes across a variety of disciplines. In some, this purpose is to exhaust all possible methods to answer a question. In others, this purpose is rooted in an effort to examine phenomena from different perspectives. Tashakkori and Creswell (2007) defined mixed methods as “research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study.” Procedural standards for mixed methods designs have been developed (Creswell & Plano Clark, 2007; Leech & Onwuegbuzie, 2009; Miller & Gatta, 2006), and Creswell and Plano Clark (2007) describe a variety of the components, procedural steps, benefits, and drawbacks of four mixed methods designs. These four designs are the triangulation design, the embedded design, the explanatory design, and the exploratory designed. This study employed the embedded design, which is defined by Creswell and Plano Clark (2007) as, “a mixed methods design in which one dataset provides a supportive, secondary role in a study based primarily on the other data type.” In this study, quantitative data was the primary source of information and qualitative data served a supportive role.

As asserted by Bartholomew and Brown (2012), cross-cultural psychology research often involves exploring phenomena that were originally developed within mainstream Western culture and attempting to extend the range of variation seen in these constructs. Utilizing a mixed methods approach allows for an emphasis on the experience of participants and observations of behavior as they occur naturally through qualitative data as well as a reduction of potential bias through quantitative data. Further, mixed methods provides a way to explore a construct, such as health services use in the present study, thoroughly within its context and to generalize to this context. The use of mixed methods in cross cultural psychology is supported researchers. For instance, researchers have suggested using multiple methods as a means to provide more

complete understandings of phenomena within cultural contexts (Church & Katigbak, 2002; Diaz-Loving, 2005; Kim & Berry, 1993). Others have continued to explore the utility of mixed methods across psychology in general (Gelo, Braakmann, & Benetika, 2008) and its subfields, including counseling psychology (Hanson, Creswell, Plano Clark, Petska, & Creswell, 2005), crosscultural psychology (Harkness et al., 2006; Karasz & Singeli, 2009), developmental psychology (Harkness et al., 2006; Yoshikawa, Weisner, Kalil, & Way, 2008), multicultural counseling (Plano Clark & Wang, 2010), traumatic stress research (Creswell & Zhang, 2009), and school psychology (Powell, Mihalas, Onwuegbuzie, Suldo, & Daley, 2008).

## **Participants**

### **Medical chart review.**

A sample of 53 Latinos diagnosed with lung and head-and-neck cancers during the years 2007 and 2008 was drawn. Their ages ranged from 23-88 ( $M = 57.07$ ,  $SD = 16.26$ ), and males accounted for 57.5% of the sample and females accounted for 42.5%. These patients originated from either the USA (55%) or a Latin American country (45%), and the majority of participants preferred English (62.5%) over Spanish (37.5%). Head-and-neck cancer was diagnosed in 57.5% of these patients, and lung cancer was diagnosed in 42.5% of the patients. Cancer was diagnosed as Stage I in 37.5%, Stage II in 2.5%, Stage III in 15.0%, or Stage IV in 42.5% of patients. The number of co-occurring illnesses for these patients ranged from 2-17 ( $M = 4.8$ ,  $SD = 3.84$ ).

### **Interviews and focus groups.**

Interviews were conducted with key informants and Latino patients diagnosed with lung and head-and-neck cancers, and focus groups were conducted with patient caregivers and patient navigators. Seven key informants involved in the diagnosis and/or treatment of Latinos diagnosed with lung and head-and-neck cancers at a safety-net hospital in Denver, CO were

interviewed. These key informants were chosen by creating lists of health care providers from each medical division involved in the treatment of lung and head-and-neck cancers and selecting one key informant from each list to invite to participate in the study. Information about the key informants (e.g., professional role, time in this role, institutional affiliation, and training received) was collected prior to their interviews. This study included participation from a pulmonologist, an oncologist/hematologist, an oncology nurse, an oncology pharmacist, an otolaryngologist, a lung surgeon, and a radiation oncologist. Information about the key informant participants (e.g., ethnicity and number of years at the hospital) was obtained from a socio-demographic questionnaire they were asked to fill out at the time of their interviews. (Demographic information from one key informant was not collected.) Six key informants identified as white, and two females and five males were interviewed. Their time at the hospital ranged from nine months to ten years ( $M = 5.46$ ,  $SD = 3.28$ ).

Participants in this study also included nine patients diagnosed with lung (four patients) and head-and-neck (five patients) cancers. These participants were chosen by randomly selecting patients from the registry of Latinos diagnosed with lung and head-and-neck cancers between 2007 and 2008. Interviews continued until it became apparent that saturation had been reached, which occurred when no new information was being provided in the interviews. Information about the patient participants (e.g., age, marital status, education level, employment status, occupation, income, insurance status, years in the United States, cancer diagnosis, and type of treatment received) was obtained from a socio-demographic questionnaire they were asked to fill out at the time of their interviews and are presented with descriptive statistics. The patients' ages ranged from 49 to 75 ( $M = 61.80$ ,  $SD = 9.64$ ), and they included four females and five males. The number of years of schooling ranged from one year of elementary school to graduating from

high school ( $M = 8.11$ ,  $SD = 4.23$ ). None of the patients were currently employed, and they had previously held jobs in labor fields (i.e., laundry worker, migrant farmer), in automobile sales, and as housewives. Their household monthly incomes ranged from less than \$1,000 (56%) to \$1,001 to \$2,000 (44%). None of the patients had private health insurance, and some received health care benefits from Medicare (44%) and Medicaid (44%). Some of the patients had spent their entire lives in the United States (44%), and others had come to the United States between four years and 40 years prior ( $M = 14.20$ ,  $SD = 14.60$ ). The types of treatment received by the patients included chemotherapy alone (two patients), radiation and chemotherapy combined (three patients), and biological therapy alone (one patient).

In addition to key informants and patients, caregivers of patients diagnosed with lung and head-and-neck cancers were included in this study. These caregivers were chosen for participation by randomly selecting patients from the cancer registry. From this random selection, the patients' caregivers were contacted to request their participation. This procedure was repeated until six caregivers were obtained for participation. Of the participants, two were caring for head-and-neck cancer patients and four were caring for lung cancer patients. The caregivers ranged in age from 34 to 59 years ( $M = 46.67$ ,  $SD = 10.31$ ), and five female caregivers and one male caregiver participated in this study. Three of the caregivers reported having employment and three reported being unemployed.

Finally, seven current patient navigators for breast, prostate, and colorectal cancer at the safety-net hospital in Denver, CO were included in this study. These individuals participated in a focus group interview for this study on a volunteer basis. Five patient navigators were female and two were male. Navigators reported working at the hospital from two to nine years ( $M =$

3.43, SD = 2.57). Only one navigator reported previous experience as a patient navigator. Six of the navigators identified as Hispanic, and one navigator identified as non-Hispanic.

## **Measures**

### **Medical chart review.**

Patients' clinical charts were reviewed to assess the time that elapsed between their cancer diagnosis and the time they began their treatment. Information about 1) type and stage of cancer diagnosis, 2) date when the patient first presented with symptoms or obtained an abnormal X-ray that suggested the possible presence of lung and/or head-and-neck cancer; 3) date when the patient was diagnosed with Stage I, II, IIA, IIIB, or IV cancer; 4) date when the patient began the recommended treatment course; and 5) type of treatment(s) received was recorded. Additional data obtained included age, gender, ethnicity, marital status, country of origin, homelessness status, language preference, city and state of residence, comorbid conditions, insurance type, amount of insurance co-pay, location of primary care provider, income, house size, side effects experienced during treatment, alcohol and tobacco use, family history of cancer, and date of death, if occurred.

### **Interviews and focus groups.**

Questions used for key informants (see Appendix A), patients and caregivers (see Appendix B), and patient navigators (see Appendix C) can be found in the appendices.

### **Socio-demographic questionnaires.**

Patient questionnaires (see Appendix D) asked about characteristics such as their age, gender, education level, employment status, and income level. Caregivers (see Appendix D) were asked to provide information about their age, gender, employment status, and to report the cancer site of his or her patient. Each key informant (see Appendix E) was asked to provide some

brief background information, such as his or her ethnicity, length of time he or she has been providing services, and the roles he or she serve for cancer patients. Patient navigator questionnaires (see Appendix F) asked about characteristics such as gender, ethnicity, number of years working at the hospital, and whether or not he or she had previous experience as a patient navigator.

## **Procedure**

### **Medical chart review.**

To comply with Colorado's Health Insurance Portability and Accountability Act (HIPAA), 53 patient charts were reviewed by personnel at the safety-net hospital in Denver, CO, who were authorized to have access to patients' confidential medical information. This individual was trained to use an electronic template to record data fields to extract the information of interest in this study.

### **Interviews and focus groups.**

After receiving consent from the participants, patients, caregivers, patient navigators, and key informants filled out a socio-demographic form. Then, the patients and key informants participated in semi-structured interviews, and caregivers and patient navigators participated in focus groups. These interviews and focus groups allowed rich, in-depth information from the patients, caregivers, providers, and navigators to be gathered. Each interview or focus group ranged from 30 minutes to one hour in length and was audio taped for later transcription and analysis. The semi-structured interviews with patients and the focus group with caregivers (see Appendix A) focused on their experiences through cancer diagnosis and treatment, accessing and receiving care at the hospital, as well as any difficulties they encountered throughout the process. The semi-structured interviews with key informants (see Appendix B) and focus group with

navigators (see Appendix C) addressed the system and patient factors that health care providers identified as impactful on the care of Latinos diagnosed with lung and head-and-neck cancers. Additionally, all participants were asked for their recommendations for a future patient navigation program to serve Latinos diagnosed with lung and head-and-neck cancers at the hospital.

## **Results**

### **Data Management and Analyses**

Fifty-three medical charts were reviewed, and this data was managed and analyzed using IBM SPSS 20.0. Participants who did not have data for the outcome variable ( $n = 12$ ), time elapsed between cancer diagnosis and beginning of treatment, were excluded. Additionally, one influential case was also dropped. Thus, a total of 40 participants were entered in the final analyses.

The interview and focus group data was managed and analyzed using ATLAS.ti, a qualitative software to organize and analyze qualitative data.

### **Analysis**

#### **Medical chart review.**

To test hypotheses 1-3, a backwards method multiple regression analysis was used. This method was also appropriate due to the exploratory nature of the analysis. The dependent variable was time from diagnosis to treatment as measured by the number of days from diagnosis of cancer to first treatment for this diagnosis. Prior to conducting the multiple regression analysis, three variables, Age, Stage at Diagnosis, and Charlson Comorbid Conditions Status Sum, were converted into z-scores to center the data. To test hypothesis 1, the independent variables were Age (in years), Country of Origin (either United States or a Latin American

country), US Citizenship (yes or no), Language (English- or Spanish-speaking), and Gender (Male or Female). To test hypothesis 2, the independent variables were Stage at Diagnosis (Stage I, Stage II, Stage III, or Stage IV) and Charlson Comorbid Conditions Status Sum (the number of co-occurring illnesses). To test hypothesis 3, the independent variables were Insurance Type (Medicare/Medicaid vs Other (CICP/CHS)) and Homelessness (yes or no). Additionally, all independent variables were analyzed together in one model and a post-hoc power analysis was conducted to assess if there was enough power with a sample size of 40 participants and 9 independent variables.

Correlations between time from diagnosis to treatment and all predictors (Age, Country of Origin, US Citizenship, Language, Gender, Stage at Diagnosis, Charlson Comorbid Conditions Status Sum, Insurance Type, and Homelessness) were also computed (see Table 7). This analysis was run to examine in isolation 1) the relationship of each predictor to the dependent variable, apart from their relationship to other predictors, and 2) the interrelationship among the predictors, apart from their relationship to the dependent variable. .

In addition to these analyses, frequencies and percentages for Country of Origin (see Table 1), Language (see Table 2), Gender (see Table 3), Cancer Site (see Table 4), Insurance Type (see Table 5), and Homelessness (see Table 6) were calculated.

The regression model that examined predisposing factors alone was not found to predict delay from diagnosis to treatment,  $R = .25$ ,  $R^2 = .063$ ,  $F(5, 34) = .46$ ,  $p = .81$ .

The regression model that examined enabling factors alone was not found to predict delay from diagnosis to treatment,  $R = .04$ ,  $R^2 = .00$ ,  $F(2, 36) = .03$ ,  $p = .97$ .

The regression model that examined need factors alone was not found to predict delay from diagnosis to treatment,  $R = .38$ ,  $R^2 = .14$ ,  $F(3, 35) = 1.94$ ,  $p = .14$ .

An inclusive regression model that included all independent variables (Age, Country of Origin, US Citizenship, Language, Gender, Stage at Diagnosis, Charlson Comorbid Conditions Status Sum, Insurance Type, and Homelessness) was found to predict 32% of the variance in delay from diagnosis until treatment,  $R = .56$ ,  $R^2 = .32$ ,  $F(10, 27) = 1.25$ ,  $p = .31$ . In this model, the need factor of Charlson Comorbid Conditions Status Sum was found to be a significant predictor. An inverse relationship was shown, indicating that individuals with more comorbid conditions experienced fewer days from diagnosis to treatment. With each additional comorbid condition, time from diagnosis to treatment decreased by 18.72 days. This model also showed the predisposing factor of Gender was a significant predictor. Females experienced more days from diagnosis to treatment than males. An interaction revealed that, when compared to males, females with a low number of comorbid conditions experienced the longest delays in time from diagnosis to treatment. Figure 1 depicts the significant interaction that was found in this study between Charlson Comorbid Condition Status Sum and Gender,  $F(2, 21) = 3.68$ ,  $p = .04$ . A post-hoc power analysis using G\*Power 3 (1992-2009) indicated that there was enough power (76%) to detect a large effect sizes of 0.47 ( $p = 0.05$ ) with 40 participants and nine independent variables.

The computed correlations indicated that only gender ( $p < .05$ ) and comorbid conditions ( $p < .01$ ) had an independent relationship with time from diagnosis to treatment, with all other variables tested in isolation being only minimally related to such time. These findings confirm that the current sample size might be adequate to detect the predictive relationship of the independent variables and interactions tested in the all-inclusive model.

### **Interviews and focus groups.**

To address research questions 1-4, the transcripts of the recordings of the in depth interviews of key informants and patients and the focus groups with caregivers and patient navigators were analyzed utilizing Ethnographic Content Analysis (Altheide, 1987). This method allowed the extraction of the themes of interest in this study. It should be noted that the process outlined by Krippendorff (2004) has traditionally been used for and thought to apply to quantitative methods of analyzing qualitative data. However, Krippendorff (2004) asserts that, “quantification is not a defining criterion for content analysis.” Additionally, Krippendorff (2004) outlines a method of qualitatively approaching Content Analysis, termed Ethnographic Content Analysis, which is reflected in the following description of this study’s methodology.

According to Krippendorff, Ethnographic Content Analysis is ideal for pulling out trends that take place across interviews and for pulling out attitudes, interests, and values expressed in those trends (2004). This process involves several steps that were used in the analysis of the data collected in this study. As outlined by Krippendorff, these steps are as follows: (1) *unitizing*, which involves identifying parts of the text that represent a common theme and assigning these parts to categories based on these themes; (2) *sampling*; (3) *coding*, which involves developing a coding scheme guided by the research questions that allows for examining the text for very specific data; (4) *reducing*, which involves assigning the themes to broader categories to make the data more manageable; (5) *inferring*, which involves assessing the data to determine its meaning within the context of the research questions; and (6) *narrating*, which involves explaining the results in an understandable way (2004). Thus, the ultimate explanation of the relevant themes is in narrative form.

The above steps were adhered to throughout the process of analysis by research assistants who were trained by the Project Leader, who has expertise in Ethnographic Content Analysis. This training began with all research assistants analyzing the same transcript. Their initial analysis included individually reading the transcript, making note of significant segments, and giving these quotes one- to three-word labels (*unitizing* and *sampling*). Following this initial step, the research team met as a group to review the segments and labels that had been identified by each member. This review process also included grouping the labels into categories based on the questions posed in the interviews and focus groups conducted (*coding* and *reducing*). Once agreement had been reached between research assistants on the labels and categories for the first interview transcript, the research assistants divided into groups of two to analyze the remaining transcripts. The research assistants followed the steps described above, first categorizing, sampling, coding, and reducing the interview transcripts individually, then meeting with their partners to compare their analyses, and then meeting with the research team as a whole to relay new codes that had emerged and pose any questions that had arisen. This process continued until all transcripts had been analyzed.

After all transcripts had been analyzed, the research team began *inferring* and *narrating* the coding that had been completed in the previous steps. Again, the research assistants were paired into groups to develop themes, or sentences that described the labels that had been previously decided upon. The research assistants then met with the whole research team to discuss the themes they had written. Finally, the research assistants expanded upon these themes to complete the *narrating* process. As explained above, the narration of the labels in addition to significant quotes that were coded by the labels is the final explanation of the data collected.

*Research question 1.* What *predisposing factors* do patients, caregivers, providers, and patient navigators identify as influential on time from diagnosis to treatment for Latinos diagnosed with lung and head-and-neck cancers?

Participants identified several predisposing factors as having an impact on the time to treatment for Latinos diagnosed with lung and head-and-neck cancers, including health competency, health beliefs, language, living conditions, and psychological resources. According to many key informants, Latino patients diagnosed with lung and head-and-neck cancer often have limited “health competency.” Latino cancer patients often lack the health competency to understand the process they are going through. This may even result in not understanding that they need to follow-up with their appointments, as noted by one key informant, “Sometimes the patient has no idea that they have to come back. Even though we tell them we want them back, they have no idea why.” This broader category of “health competency” can be further broken down into the following themes: difficulties understanding medical information, understanding their own bodies, understanding the medical system, and understanding their role in treatment. Latino cancer patients often have a difficult time understanding the information given to them by health care providers. This can make the process of treatment very difficult, as suggested by one key informant, “And also there is a lack of understanding from the patient of what is required to be successful when they’re in treatment.” Additionally, some Latino cancer patients do not understand what is happening with their bodies. This may mean that these patients do not understand the significance of their diagnosis or treatment, as reported by one key informant, “Some of them don’t, can’t fathom what’s happening. Some of them worry more about the incision on the skin than the fact that they may die.” This key informant’s observation is supported by the evidence provided by the patients’ frequent statements that they were unsure of

their disease prognosis. This is illustrated in the following dialogue between the interviewer and a patient:

Interviewer: What stage did they tell you it was?

Patient: Hmm.

Interviewer: One, two, or three?

Patient: What stage? No.

Interviewer: You don't remember?

Patient: I don't remember.

Latino cancer patients often also have a difficult time “navigating the medical system.” They are often unsure of where to go for appointments and resources. This may lead to frustration with the medical system, as noted by one key informant, “They may have been frustrated by the system and not understanding it.” Finally, many key informants asserted the importance of Latino cancer patients understanding their role in treatment. This role may include following up with appointments and completing enrollment for financial resources for their treatment.

As discussed by several key informants, Latino cancer patients hold some beliefs, such as the effectiveness of home remedies, mistrust in surgery, and feeling well means you are well, about health practices that differ greatly from common beliefs in the United States. As described by one patient navigator,

The health belief that unless you feel sick, you're not sick. So there's often a disconnect between what the doctor is telling the patient and how the patient feels. So, I think that even when patients are respectful to the physician or the clinician, it doesn't mean that they believe what they're hearing. I think often the navigators are in the position to have to try to convince them that, yes, there is something wrong.

Patients indicated that complementary treatments, such as spiritual leaders being available and alternative methods are important to them. Patients did not indicate that this factor is a barrier in their treatment journeys, but they did suggest that these complementary treatments could be better included in their treatment.

The impact of language was particularly important for key informants in explaining this issue as they asserted that there is a huge language barrier for Latino cancer patients, and it should be dealt with. As one key informant simply stated, “If they do not speak English, they are in big trouble.” Key informants illustrated that this issue is further complicated by some patients’ self-inhibition of language difficulties. Some patients do not share that they do not understand because they are afraid of being judged. One key informant states, “So I think language, and I think that if they don’t speak English, I think they’re fairly shy about it because they’re proud, very proud people. And if they don’t know the language, I think they almost feel guilty, which is unfortunate.” Patients also indicated that patients and family members who do not speak English sometimes had difficulties communicating with their providers as an interpreter was not always available.

“Trust” is a significant issue discussed by both key informants and patients. Key informants assert that because of differences in culture and language, it is important for health care providers to build relationships with Latino cancer patients in order to develop trust with them. It is significant for this to happen as it may result in patients adhering to their treatment plans, as suggested by one key informant,

I think that we see that with a lot of our patients. Umm, and some of that is just because life is so hard and they may have been frustrated by the system and not understanding it, they feel like they’re being jerked around or their being used as guinea pigs or they’re not being told the whole story. So there are some of those issues that may come into play. And then there are other folks out there who will be completely trusting and say whatever you want to do is ok. But we really find that if we’re able to build that trust and build rapport and good relationship with our patients the bond is better, we get better adherence to the plan, better follow through.

More specifically, this lack of trust may center on concern for being made to be a “guinea pig” for research or for providers omitting information. Latino cancer patients may not trust their

health care providers because they are afraid of being experimented on, which may come from such terminology as “clinical trials” and “investigations.” As explained by one patient navigator,

They are so afraid of the word “Investigation” or “clinical trial” that they don’t even realize how we are going to help them because they are so blinded by the word “investigation.” So yesterday I had a patient that I have to talk to him over the phone for an hour, and explain to him that this program was going to help him to overcome barriers and we weren’t going to use the patient as a guinea pig because they have that in mind.

Mental health concerns were discussed by key informants and patients as potential barriers to quality care for patients. The treatment journey impacts and is impacted by the mental health of Latino cancer patients. Mental health issues may include substance abuse, depression, coping through denial, and behavioral change.

Substance abuse by some Latino cancer patients may play an important causal role in cancer. Additionally, it may make treatment difficult. As suggested by one key informant,

Yeah well that’s a problem number one that they sometimes have to actually quit these other complications, for them to alcohol or drugs and you know, sometimes that doesn’t happen. And some other times, I mean, we are dealing with patients that have abusive behavior so it’s not just that maybe they don’t take drugs, or smoke or drink anymore but they ask, you know, for help or they ask for more medications that way if they want to abuse the system. So they are not abusing the drugs but they are trying to abuse the system and that abusive behavior makes the relationship and the treatment more difficult.

Depression may be a part of the treatment journey of Latino cancer patients, and it may be further complicated by alcoholism. As illustrated by one key informant, “And people that drink have depression. Uh, either it’s generated by the alcoholism or it’s preceding alcoholism where they drink because they’re depressed.” Some Latino cancer patients cope with their cancer through denial. For one key informant, this method of coping is the first barrier, “I think the first barrier is denial. Patient denial.”

Patients also asserted the emotional burden they experienced while dealing with their cancer, and they indicated feeling anxiety and depression about their diagnosis. This burden was

illustrated by one patient, “I think a lot. My mind is working 24/7 just thinking about this thing in my throat.” Another patient illustrated their anxiety by saying, “I feel paranoid.”

Many patients also discussed feeling afraid after learning of their cancer diagnoses and throughout their treatment journeys. This fear centered on three main themes: fear of cancer, the unknown, and treatment. One patient explained that she did not pursue much information about her diagnosis because she was scared of her cancer but that she later felt having more information may have eased some of her concerns.

Interviewer: Looking back do you feel that you would have been helped if you would have learned more about your cancer diagnosis if you felt like you needed more information?

Patient: Yes, I think so because I was pretty scared.

Patients also did not know what to expect after receiving their diagnoses, and this ambiguity was scary for them, as indicated by one patient:

Interviewer: So when you get diagnosed, right after, that’s when it’s really scary?

Patient: That’s when the fear starts, you know, fear of the unknown I guess, you know? You don’t know what you are gonna go through.

Fear of the treatment process also had a significant impact on patients’ treatment journeys as it caused some to delay pursuing their treatment. This was illustrated by one patient:

Patient: Yup, I was the first chemo, after we found out, I missed my first, scared, I missed my first appointment.

Interviewer: Because you were scared?

Patient: Because I was scared. Same with radiation. Missed the first appointment.

Interviewer: Tell me more about that. What happened?

Patient: I just panicked, you know. Like if I don’t go, it’ll go away. It wasn’t going away, but I just scared myself. And then I talked to friends, and they were like, ‘Oh, you don’t want to take chemo, it’s gonna...’ You know, I just scared myself out of it, out of both first appointments. Then after I was here it was fine, you know?

**Research question 2.** What *enabling factors* do patients, caregivers, providers, and patient navigators identify as influential on time from diagnosis to treatment for Latinos diagnosed with lung and head-and-neck cancers?

Participants identified several enabling factors as having an impact the time to treatment for Latinos diagnosed with lung and head-and-neck cancers, including financial status, insurance status, immigration status, availability of transportation, and social support. Factors related to socio-economic status were prominent in discussions with key informants and patients as they are seen as barriers to adequate health care. These factors include financial barriers, lack of money for transportation, burden of insurance co-pays, job loss, insurance status, immigration status, and living conditions. Financial barriers are a significant problem to accessing quality health care, but the hospital works to provide access despite these difficulties. This effort was emphasized by one key informant,

Yes, I think that people who work here are very focused in giving the best options to the patients even though sometimes the resources are not great. And people have the experience to deal with these types of patients and this type of situation so they become experts and you know, maybe getting medication that are very expensive for people who don't have money to pay for these medications. So that part of, you know, the patient that doesn't have any medical resources, and people who have the knowledge, works very well. And I think it's something that you know that [this hospital] has. Um, yeah that's why I think it's the best.

Specific financial barriers discussed by both key informants and patients include lacking money for transportation and lacking money for co-pays. Latino cancer patients often have a difficult time paying for or finding the transportation necessary to get them to their appointments.

Without the ability to pay for co-pays, many Latino cancer patients are unable to access necessary medical care. These financial barriers may be further complicated when unexpected consequences of cancer and its treatment, such as job loss occur, as indicated by one patient, "And then when I started going to treatment, I started getting weaker and weaker and weaker where I couldn't even go do a temp job."

Accessing appropriate medical care can also be influenced by the insurance status of patients. Insurance status impacts the health care options available to patients. Without coverage

for health care, it can be difficult for Latino cancer patients to access care, as asserted by one key informant,

People do not have good health coverage and have a hard time accessing the system. And there's some things we cannot do for people who do not have good coverage at [this hospital]. For patients who do have good coverage there is one of those things called a PET scan, which is used for staging lung cancer to see how advanced it is.

Further, accessing health care is even more difficult for patients who do not have health insurance. Latino cancer patients who do not have insurance have limited health care resources. In particular, it is suggested that these patients may have a difficult time receiving radiation therapy, as explained by one key informant, "If they need radiation therapy, there may be limitations based on if they have no insurance." Lack of health insurance was particularly distressing for some patients, causing them to worry that they may not be able to receive treatment following their diagnosis. This was illustrated by one patient, who stated, "I didn't know that cause I didn't have insurance I thought well, you see on TV where you can't. And he said, 'Don't worry about that, we're gonna treat you, don't worry.'" Patients indicated that they were able to get their health costs covered through various methods, such as Medicaid, Medicare, and the Colorado Indigent Care Program (CICP).

Another factor that may greatly influence a patient's ability to access health care is immigration status. Latino cancer patients that lack documentation have an even more difficult time accessing health care, as asserted by one key informant, "Well that can be difficult for patients in terms of getting the drugs that they need. If they're undocumented and there is a patient assistance program available through pharmaceutical companies to provide drugs at low cost or free or undocumented patients don't qualify."

As previously indicated, patients often struggled to find and afford transportation to and from their medical appointments. Some patients were able to receive various forms of assistance

with this issue. These resources included tokens and cards to pay for bus fares, vouchers to pay for cab fares, Adjusted Care to transport them to and from appointments, and family members who were able to transport the patients to and from the hospital. As described by one patient, these resources were particularly helpful for patients during their treatment, “When I was really sick I was getting vouchers for the cab. I wouldn’t have to get on the bus, so that was good.”

Financial difficulties were also indicated as barriers to patients during their treatment journeys. Patients had financial difficulties while dealing with their cancer, and they received support for these difficulties through various resources, such as the Low Income Energy Assistance Program (LEAP), Social Security, food stamps, discount cards, and the treating hospital itself. Dealing with their cancer made it difficult for patients to pay for typical living expenses, such as food, rent, and cell phone bills, and they were connected to resources, such as community resources and the Diane Fisher Foundation, to help them with paying for these types of expenses. As described by one patients, “I was still getting the Diane Fisher Foundation, cause I’m still under Dr. ###’s care once a month. It takes me and my wife to dinner, something that we can’t afford, and they pay for it, you know, once a month, so that’s a good thing.”

Social support is important during treatment, and it is suggested that this support can found with families, friends, and support groups. However, some patients do not have the support they need. Without this social support, the process of treatment can be even more difficult for patients, as noted by one key informant, “A lot of our patients have no support system. So if they get sick they have no one to help them. And that’s tough, really tough.” Some patients do have strong social support, particularly from their families, and key informants often asserted that this factor is very helpful to patients as they go through their treatment journeys. This point is illustrated by one key informant, “And I have one man that lost his larynx from

laryngeal cancer, and his sister, his wicked sister, brings him in and she's just a riot, but she keeps on this guy like you can't believe. She has him here on time, all the time. If it's up to him, he would probably not show up." Many patients discussed the role their families played during their treatment journeys. It was very significant for the patients and their family members for the family to be involved in their health care. Family members did things like attend treatment appointments, help patients with transportation, and assist in decision making. As illustrated by one caregiver, "I'm not working, but I have a big family so if I need something, I just go to them. We're all there for each other."

**Research Question 3.** What *need factors* do patients, caregivers, providers, and patient navigators identify as influential on time from diagnosis to treatment for Latinos diagnosed with lung and head-and-neck cancers?

Participants identified the need factor of perceived need for health care services. For example, for several patients, their cancer diagnosis was unexpected due to a lack of symptoms or due to symptoms that were overlooked. As indicated by one patient,

It was just that I found out just what a sneaky disease cancer is cause I never felt sick, you know what I mean? I never, and if it wasn't for the food getting stuck in my throat right there, I would have never come in. I thought my tooth was causing an infection in my mouth, you know, and then it's so sneaky I never realized I was sick until they did the biopsy and they told me I was sick. I felt great.

Some patients did indicate experiencing symptoms, such as not feeling well and having pain in their throats, prior to their diagnoses.

**Research Question 4.** What *additional factors* do patients, caregivers, providers, and patient navigators identify as influential on time from diagnosis to treatment for Latinos diagnosed with lung and head-and-neck cancers?

Participants emphasized the influence of *fear* on time to treatment for Latinos diagnosed with lung and head-and-neck cancers. Many patients also discussed feeling afraid after learning of their cancer diagnoses and throughout their treatment journeys. This *fear* centered on three main themes: fear of cancer, the unknown, and treatment. One patient explained that she did not pursue much information about her diagnosis because she was scared of her cancer but that she later felt having more information may have eased some of her concerns.

Interviewer: Looking back do you feel that you would have been helped if you would have learned more about your cancer diagnosis if you felt like you needed more information?

Patient: Yes, I think so because I was pretty scared.

Patients also did not know what to expect after receiving their diagnoses, and this ambiguity was scary for them, as indicated by one patient:

Interviewer: So when you get diagnosed, right after, that's when it's really scary?

Patient: That's when the fear starts, you know, fear of the unknown I guess, you know? You don't know what you are gonna go through.

Fear of the treatment process also had a significant impact on patients' treatment journeys as it caused some to delay pursuing their treatment. This was illustrated by one patient:

Patient: Yup, I was the first chemo, after we found out, I missed my first, scared, I missed my first appointment.

Interviewer: Because you were scared?

Patient: Because I was scared. Same with radiation. Missed the first appointment.

Interviewer: Tell me more about that. What happened?

Patient: I just panicked, you know. Like if I don't go, it'll go away. It wasn't going away, but I just scared myself. And then I talked to friends, and they were like, 'Oh, you don't want to take chemo, it's gonna...' You know, I just scared myself out of it, out of both first appointments. Then after I was here it was fine, you know?

## **Discussion**

Evidence shows that Latino cancer patients have poorer survival rates, later-stage presentations, and an increased likelihood of being lost to follow-up than patients from other ethnic groups, and that particularly patients with lung and head-and-neck cancers typically

experience difficult and complex treatment journeys. It is important that patients of these types of cancers receive timely and appropriate treatment due to the relative complexity of these cancers as well as the high mortality risks associated with them. Given this information, this study sought to establish a relationship between the factors suggested by the Behavioral Model for Vulnerable Populations and time from diagnosis to treatment for Latino patients diagnosed with lung and head-and-neck cancers.

### **Interpretation of Results**

Regression analysis demonstrated that, when taken separately, neither predisposing, enabling, nor need factors are significant predictors of time from diagnosis to treatment for Latinos diagnosed with lung and head-and-neck cancers. That is, none of these components alone is sufficient to explain the utilization of health care services use, conceptualized as time to treatment in the present study. This is consistent with the Behavioral Model of Health Services Use, which asserts that the behavior of utilizing health services is an outcome of a complex pattern of interactions between predisposing, enabling, and need components. When these components were taken together, the model accounted for 32% of the variance. Within this model, the predisposing factor of Gender was shown to be a marginally significant predictor, demonstrating that females experienced more days from diagnosis to treatment. The need factor of the Charlson Comorbid Conditions Status Sum was shown to be a significant predictor, demonstrating an inverse relationship by which individuals with more comorbid conditions experienced fewer days from diagnosis to treatment. Further, with each additional comorbid condition, delay decreased by 18.72 days. A significant interaction between these two predictors was also observed, as in previous analysis. This interaction suggests that the relationship between number of comorbid conditions and time to treatment is most relevant for females as

females with the fewest number of comorbid conditions experienced the longest delay in time from diagnosis to treatment.

Analysis of the qualitative data collected through interviews and focus groups conducted with patients, key informants, caregivers, and patient navigators demonstrated evidence of the impact of predisposing, enabling, and need factors on the time from diagnosis to treatment. Some of these factors were tested in the regression analysis, including language, insurance status, and citizenship. Although none of these factors alone was shown to be a significant predictor of time from diagnosis to treatment, they were a part of a larger model that accounted for about one-third of the variance in this phenomenon. This is similar to how these factors and others were discussed by participants in the interviews and focus groups. That is, these participants did not point to one factor alone when discussing patients' or their own treatment experiences. Rather, they discussed the complex interactions of many factors having an impact on the challenges these patients encountered. This is again consistent with the assertion of the Behavioral Model of Health Services Use that utilizing health services comes out of an interaction between predisposing, enabling, and need factors.

As discussed above, the regression model only accounted for 32% of the variance in time from diagnosis to treatment, and many more of the factors identified by interview participants were not assessed through review of the patients' medical charts. Participants identified additional factors to those analyzed through the quantitative data. These additional factors include the predisposing factors of health competency, health beliefs, and trust; the enabling factors of transportation availability, living conditions, and social support; and the need factor of symptoms experienced. Gathering this qualitative data allowed for a more comprehensive view than the quantitative data could have provided alone.

The review of the patients' medical charts was limited in scope as the information they contained was only what the hospital system considers necessary for and germane to the patients' medical care. It is likely that the qualitative data allowed for a more complete view of patients' treatment experiences and that a portion of the additional 68% of the variance is accounted for by the factors discussed in the qualitative data. For instance, many patients discussed the impact fear had on their treatment experiences. They indicated that it kept them from engaging in some behaviors, such as following treatment recommendations and pursuing information about their cancer, that may have influenced the time from their diagnosis to their first treatment. It is likely that a patient's chart would have documented missing appointments or not being receptive to medical information; however, it is unlikely that the underlying reason for these behaviors, fear, would have been accessible from a review of a patient's chart. Consistent with the suggestion by Bartholomew and Brown (2012), the inclusion of qualitative data allowed for an emphasis on the experiences of the participants themselves within a cross-cultural context. Without this qualitative data, a significant portion of these patients' treatment experiences would have been missing.

The purpose of this study was to examine factors related to the time from diagnosis to treatment for Latino patients diagnosed with lung and head-and-neck cancer patients. Given the fact that all of the participants were of a low-income background and that none of the participants had private health insurance, the results of the present study may be largely related to the role of socioeconomic status rather than to the unique role of ethnicity. Thus, the results may be universally applicable to underserved populations and not just to patients of a Latino background. Additionally, a large percentage (42.5%) of the participants included in the medical chart reviews had cancer that was diagnosed at Stage IV. The literature suggests that Latinos do

typically receive diagnoses at later stages than patients of other backgrounds (Shavers et al., 2003); thus, the results of this study may also be generalizable to other populations of patients who are diagnosed at later stages.

### **Limitations**

The design of this study looked at quantitative information about factors related to time from cancer diagnosis to beginning of treatment for Latinos diagnosed with lung and head-and-neck cancers and elicited qualitative information from patients, caregivers, key informants, and patient navigators about these factors. Although valuable information and insight was gained from this research, there were some limitations to the study that should be addressed. First, patient acculturation was not accounted for by the patients' medical charts and was thus not included in the study, but it may play a role in delay from diagnosis until treatment, as suggested by Gelberg, Andersen, and Leake (2000). However, acculturation also was not mentioned during the qualitative interviews and may therefore not impact use of medical care in this population. This study was unable to fully examine the unique impact of socio-economic status on the time from diagnosis to treatment for these patients, even though many of the barrier and problems encountered are related to these patients being medically underserved. Although income could not be included in the analysis due to incomplete and inconsistent collection of this data, most patients were of a low-income background and none had private health insurance. It may be significant to evaluate the unique contributions of low socio-economic status versus the unique contribution of the Latino/a identity.

Regarding the qualitative data, potential researcher bias could have impacted the interview questions and interpretation of the qualitative data. The researchers took measures to standardize the coding procedures and interpretation of results during data analysis in order to

reduce the impact of researcher bias. For example, all data was coded by two independent researchers, whose work was subsequently reviewed by the rest of the research team to ensure consistency. The heterogeneity of the patient and caregiver samples in terms of age, gender, level of education, and length of time in the United States may be considered an additional limitation of this study, as the unique experiences of specific groups may have been lost as a result of considering information from all participants. For example, it is possible that the treatment journey experiences of individuals who have lived in the United States for their entire lives differ from the experiences of those who have spent a smaller portion of their lives in this country, perhaps due to a wide variety of factors including differences in cultural beliefs, language preference, and immigration status. Similarly, the experiences of younger adults versus older adults, males versus females, and highly educated patients versus patients with less education may differ in important ways that the current study did not capture. Additionally, the term “Latino/a” was loosely defined in this study, and thus, within group differences (e.g., level of acculturation, generation) were not taken into account. It is also important to consider that the vast majority of the patients interviewed were cancer survivors. Patients were asked to reflect back on their entire experience through their cancer care, and it is possible that this resulted in recall bias. Also, the treatment journey experience of the patients in this study may differ from those patients who did not reach survivorship. Thus, it would be beneficial for future studies to include input from patients representing various stages in the cancer care continuum.

### **Future Research**

Future research should address the limitations of the present study. Additionally, future research should examine the possible explanations for the interaction between gender and Charlson Comorbid Condition Status Sum. Previous studies have shown that Latina women have

low rates of health services use (Bazargan et al., 2004; Borrayo et al., 2009; Scarinci et al., 2003), and the interaction observed in this study may be related to the need-for component of behavioral health services use. That is, given more comorbid conditions, Latina women may have more perceived need for utilizing health care. Without the need factor of comorbid conditions, however, these women may be less likely to utilize health services.

Future research should also consider examining additional predisposing, enabling, and need factors. For instance, factors that were suggested by Gelberg, Andersen, and Leake (2000) that were not examined in this study include acculturation, childhood characteristics (e.g., foster care, abuse and neglect history, and parental illness), living conditions (e.g., running water, lead paint, and unsafe structures), criminal behavior and prison history, victimization, mental illness, psychological resources (e.g., mastery, coping, and cognitive ability), and substance abuse. Several of these factors, including living conditions, mental health, psychological resources, and substance abuse, were not examined in the quantitative data in the present study but were addressed by participants included in the qualitative data. Health competency, including health literacy, was also discussed during interviews and focus groups but was not examined as part of the medical chart reviews. Future research should consider the influence of this factor as well as education and general literacy. Instruments, such as the Health Literacy Skills Instrument (HLSI) (McCormack et al., 2010) and the Newest Vital Sign (NVS) (Weiss et al., 2005), have been developed to assess health literacy across a variety of domains, and they may be useful in quantifying patients' understanding of medical information.

Additional enabling factors that should be considered include health services volume (i.e., physician-population ratio), competing needs, availability and use of information sources, and availability of social services within patients' communities. Again, although not measured

through the review of medical records, participants in the interviews and focus groups discussed the importance of some of these additional enabling factors, including availability and use of information sources. Finally, additional need factors that should be examined in future research include perceived health status and disability status. As in Bazargan and colleagues (2004), perceived health status could be elicited by asking participants to rate the quality of their health from poor to excellent.

Previous research has suggested that patients of ethnic minority backgrounds experience discrimination in the delivery of healthcare and may also encounter poor physician behaviors that influence their access to care (Ramos et al., 2007; Langenbach, 2003). Additionally, the experience of stigmatization is discussed in the literature (Clarke, 1999; Gamba et al., 1992; Strauss, 1989). Future research should work to examine physician perceptions of patients due to differing ethnic backgrounds as well as the influence of stigma on patients' access and utilization of health services.

As previously discussed, given the socioeconomic characteristics of the sample in this study, the results may be more indicative of the impact of factors like income and health insurance status than of the unique influence of Latino background. To further examine the unique role ethnicity may play in time from diagnosis to treatment for patients diagnosed with cancer, future research should include participants from differing ethnicities. Additionally, future research may consider examining Latino patients' utilization of health services in contexts where they are underserved, such as in the United States, and where they are not an underrepresented group, such as in Latin American countries.

The analyzed correlations between predictor variables suggested some significant relationships that may warrant further exploration. For instance, Insurance Type was

significantly ( $p < .01$ ) correlated with Country of Origin and Citizenship. These relationships suggested that participants who did not originate from the United States and who did not have citizenship were less likely to have Medicare or Medicaid and were more likely to have benefits through state- or hospital-funded programs like the Colorado Indigent Care Program (CICP).

Finally, it may be useful to include participants that are involved in patients' lives outside of the caregiver role. For instance, additional family members or friends may provide unique knowledge of the patients' experiences accessing and utilizing health services.

### **Implications**

Information from this study should be harnessed to implement interventions that work to reduce the delay from time of diagnosis to first treatment for Latino lung and head-and-neck cancer patients. It would likely be beneficial for health care providers to assess for a variety of predisposing, enabling, and need factors prior to making treatment recommendations to their patients. This assessment may then be used to direct discussions with patients about the recommendations. For instance, this study demonstrated that patients who suffer from fewer comorbid conditions experience longer delays to treatment. With this knowledge, health care providers may put effort into speaking with patients with few comorbid conditions about the health care process and the importance of following up with care. Additionally, given the evidence that women experience longer delays to treatment, health care providers should consider gender-specific interventions that work to emphasize the significance of timely treatment.

As suggested above, several other factors that were identified in the analysis of the present study's qualitative data should be examined through quantitative means in future research. Additionally, these factors should be considered when developing interventions to

decrease the delay in time to treatment for Latinos diagnosed with lung and head-and-neck cancers. For instance, within the context of a safety net hospital, it may be assumed that the enabling factor of adequate financial resources is sufficient for access to health care services. However, as demonstrated in this study and as suggested by the Behavioral Model for Vulnerable Populations, this factor alone is not sufficient. Additional considerations, such as patients' health competency, available social support, and understanding of the severity of their illness, should be made.

### **Statement of Author's Values**

As an individual existing within a socio-cultural context, the author acknowledges that certain values and beliefs may have played a role in the development and presentation of this research. The author comes from a middle-class upbringing focused on a Roman Catholic belief system. She has had the fortunate circumstance of having adequate, affordable health care insurance provided to her throughout her life and thus does not have the experience of accepting less-than-appropriate medical care as status quo. Further, it was challenging at times to view the experiences of the patients participating in this study outside of that lens; that is, it was difficult to ignore qualitative evaluations of these experiences that were not up to the expectations set by the author's own experience. Additionally, the author's Roman Catholic upbringing was centered on the ideals of *social justice*, which emphasizes the life and dignity of the human person and preferential option for the poor and vulnerable. Based on these teachings, the author believes it is significant and necessary to both consider the difficulties faced by the poor and vulnerable and to work toward action for these people. These beliefs are central to the author's pursuit of this line of research and may play a role in the interpretation of the data presented.

Table 1: Characteristics of Sample

Characteristic		<i>n</i>	(%)
Country of Origin	United States of America	22	55
	Latin America	18	45
Preferred Language	English	25	62.5
	Spanish	15	37.5
Gender	Male	23	57.5
	Female	17	42.5
Cancer Site	Lung	23	57.5
	Head-and-Neck	17	42.5
Insurance Type	Medicare/Medicaid	20	50
	Other (CHP, CACP)	20	50
Homeless	Yes	3	7.5
	No	37	92.5

*Note.* *N* = 40

Table 2: Descriptive Statistics of Variables Converted to Z-Scores

Variable	Minimum	Maximum	<i>M</i>	<i>SD</i>
Age	-1.96	1.83	.0275	.949
Stage at Diagnosis	-1.18	.985	.00462	.999
Charlson Comorbid Conditions Status Sum	-.816	3.21	-.0639	1.03

Table 3: Coefficients of Predisposing Predictors of Time from Diagnosis until First Treatment

Model	Unstandardized Coefficients		Standardized Coefficients		Sig.
	<i>B</i>	<i>SE</i>	$\beta$	<i>t</i>	
Constant	34.64	8.74		3.97	.00
Age	-1.22	6.84	-.04	-.177	.86
Gender	11.29	12.07	.17	.94	.36
Country of Origin	19.63	25.69	.30	.76	.45
Language	-13.67	23.31	-.20	-.59	.56
Citizenship	-8.46	21.52	-.12	-.39	.70

*Note.* *B* = beta value; *SE* = standard error of beta;  $\beta$  = standardized beta.

\*Denotes significance at  $p < .05$ .

Table 4: Coefficients of Enabling Predictors of Time from Diagnosis until First Treatment

Model	Unstandardized Coefficients		Standardized Coefficients		Sig.
	<i>B</i>	<i>SE</i>	$\beta$	<i>t</i>	
Constant	38.42	8.10		4.75	.00
Homelessness	4.99	20.55	.04	.24	.81
Insurance Type	.78	10.95	.01	.07	.94

*Note.* *B* = beta value; *SE* = standard error of beta;  $\beta$  = standardized beta.

\*Denotes significance at  $p < .05$ .

Table 5: Coefficients of Need Predictors of Time from Diagnosis until First Treatment

Model	Unstandardized Coefficients		Standardized Coefficients	<i>t</i>	Sig.
	<i>B</i>	<i>SE</i>	$\beta$		
Constant	37.15	7.33		5.07	.00
Stage at Diagnosis	.83	5.84	.03	.14	.89
Charlson Comorbid Conditions Status Sum	-13.71	6.15	-.43	-2.23	.03*
Cancer Site	7.31	12.31	-.11	.59	.56

*Note.* *B* = beta value; *SE* = standard error of beta;  $\beta$  = standardized beta.

\*Denotes significance at  $p < .05$ .

Table 6: Coefficients of Predictors of Time from Diagnosis until First Treatment

Model	Unstandardized Coefficients		Standardized Coefficients	<i>t</i>	Sig.
	<i>B</i>	<i>SE</i>	$\beta$		
Constant	11.24	16.24		.69	.49
Age	4.88	7.92	.14	.62	.54
Stage at Diagnosis	9.26	8.86	.28	1.05	.30
Charlson Comorbid Conditions Status Sum	-18.27	6.64	-.58	-2.75	.01*
Country of Origin	15.70	27.91	.24	.563	.58
Language	-23.68	22.97	-.355	-1.03	.31
Gender	31.54	15.81	.48	2.00	.06
Citizenship	12.25	22.80	.18	.54	.60
Insurance Type	11.64	14.75	.18	.79	.44
Homelessness	7.91	25.67	.06	.31	.76
Cancer Site	12.30	15.18	.19	.81	.43

Note. *B* = beta value; *SE* = standard error of beta;  $\beta$  = standardized beta.

\*Denotes significance at  $p < .05$ .

Table 7: Correlation Matrix of Time from Diagnosis until First Treatment and Predictors

	1	2	3	4	5	6	7	8	9	10
1 Time from Diagnosis to Treatment										
2 Age	-0.04									
3 Gender	0.28*	-0.33*								
4 Country of Origin	0.03	0.18	0.05							
5 Language	-0.06	0.31*	-0.03	0.85**						
6 Citizenship	-0.05	0.00	-0.10	0.81**	0.72**					
7 Homelessness	0.03	-0.23	-0.25	-0.28*	-0.24	-0.22				
8 Insurance Type	0.04	0.28*	0.00	-0.42**	-0.27	-0.55**	-0.10			
9 Stage at Diagnosis	-0.10	0.37**	-0.59**	0.10	0.07	-0.02	0.28*	0.16		
10 Comorbid Conditions	-0.35**	0.36**	-0.14	0.05	0.06	-0.03	-0.22	0.33*	0.43**	
11 Cancer Site	-0.08	0.57**	-0.30*	-0.06	0.08	-0.10	-0.25	0.43**	0.32*	0.51**

Note.  $N = 40$ . \* $p < .05$ . \*\* $p < .01$ .

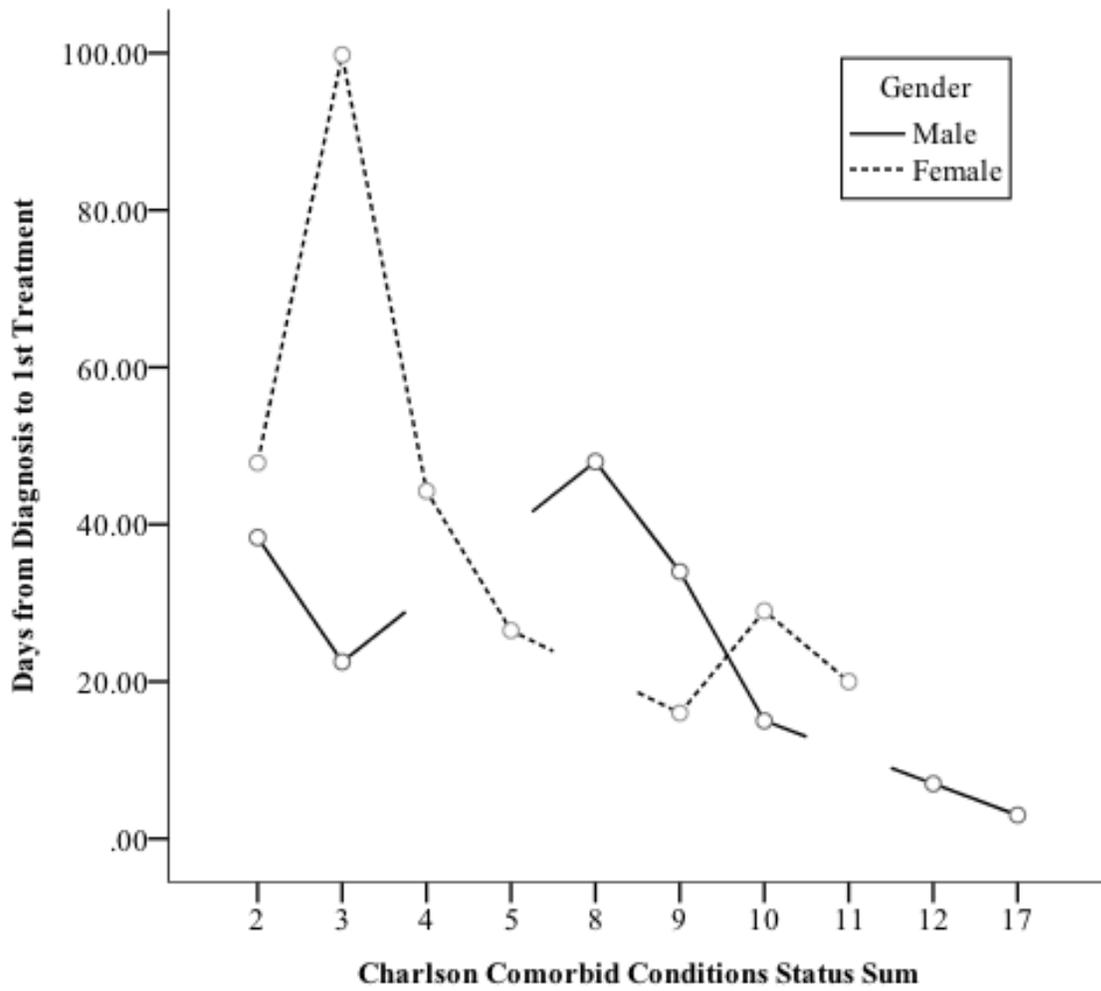


Figure 1: Interaction between Gender and Charlson Comorbid Conditions Status Sum

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## Appendix A

### Questions for Patients and Caregivers

1. Please tell us your first name and when you first found out you had cancer. Then please tell us when you began your treatment. (Use calendar as a visual aid.)
2. First we're going to look back and talk about your experience here at DH from the very first moment when you heard that your (\_\_\_\_ test) result was not normal and you needed additional testing. Let's focus on this point in time, when you first learned something might be wrong but hadn't yet learned about your diagnosis.
  - Looking back, to the time point when you found out you had an abnormal test result, what might have made this experience easier or better for you?
  - Are there things that your health care providers could have done that would have helped:
    - You during this time
    - Your family during this time
  - Are there things about the medical doctor, nurse or other staff that made it difficult for you to get the care you needed or other things that you needed?
  - Some things may get in the way and delay people going back to the doctor after they find out they have an abnormal test result.
    - Tell us about *anything* that might have delayed you going back in. (personal circumstances, other things happening in your life)
  - What DID help you during this very stressful time?
    - Someone who helped you that made a difference?
    - Something you did yourself?
  - During this time, what was most important to you?
    - Quickly knowing whether you had cancer or not?
    - Understanding everything that was going on around you?
    - The financial cost?
  - Can you tell a little bit about how you decided to go ahead towards treatment? How did you make these decisions?
  - Can you think of anything else that would have helped you?
3. Now let's move ahead to the time point when you were told that you had cancer but you had not yet started treatment. Keeping this experience in your mind for a moment, let's talk about what might have helped make this experience easier or better.
  - Looking back, what would have helped you when you learned about your cancer diagnosis?
    - Information
    - Support – someone to talk with
    - Better access to my health care provider
  - Some things may get in the way and delay people beginning treatment.
    - Please tell us about anything that might have delayed you in making treatment decisions or beginning treatment.

- After you learned of your diagnosis, what would have helped you while you were making decisions about treatment
    - Information
    - Someone to talk with
    - Better access to my health care provider (answer my questions, etc.)
  - Are there things that your health care providers could have done that would have helped:
    - You in your decision-making about treatment
    - Your family during this time of diagnosis and treatment
  - Are there things about the medical doctor, nurse or other staff that made it difficult for you to get the care you needed or other things that you needed?
  - What DID help you during this very stressful time?
    - Someone who helped you that made a difference?
    - Something you did yourself?
  - Anything else that would have helped you?
4. Looking back over the time you were in treatment, whether it was chemo, radiation, surgery, or any combination of these, what would have helped you get through your cancer treatment?
- Information
  - Transportation
  - Better access to my health care provider
  - Someone to answer my questions
  - Support and information about insurance
  - Financial resources---rent, other expenses
  - Are there things your health care providers could have done that would have helped:
    - You during treatment?
    - Your family during your treatment?
    - Anything else that would have helped you?
  - Are there things about the medical doctor, nurse or other staff that made it difficult for you to get the care you needed or other things that you needed?
  - What DID help you during this very stressful time?
    - Someone who helped you that made a difference?
    - Something you did yourself?
5. This question is specific to your experience as a Latino/a. We would like to know if there are aspects of your cultural background, beliefs, or ways of doing things or communicating that need to be considered when you receive treatment for your cancer, specifically:
- How should family members be included or not in the treatment decisions?
  - Are there some particularly inappropriate or discouraging ways of doing things or communicating that makes Latino/as distrust their providers or the system?
  - What cultural aspects need to be understood and respect for Latino/a patients?
  - What behaviors or ways of communicating would show respect for your culture or your people that you would like to see or receive during your treatment care?

- Should other community supports be included for some Latino/a patients, for example clergy or providers of alternative medicine (e.g., herbalist, curandero/a).
6. We need your help in figuring out how to help people with some of these things you talked about earlier. We've thought about a program where you may have a trained person help you through the process from the moment you have an abnormal test result, and, if you do have cancer, who will help you through the time of diagnosis, treatment decisions and treatment.
    - What kinds of services would be helpful?
    - What else could this program provide to help people from first moment of an abnormal test through to the end of treatment?
    - We'd really like your ideas for naming this staff person who will be helping patients. What would you call this position?
  7. This last question is about the possibility of receiving counseling support through the telephone. This would be a program where you could get professional support and information over the phone at two key points during the cancer experience.
    - What would it be like to receive counseling and assistance over the phone:
      - after you hear you have abnormal test results?
      - when you find out you have cancer and you're making decisions about your treatment?
      - would it be helpful if this person also helped you get ready/prepare for treatment?
      - What should this program look like? What should be included?

Is there anything we've forgotten to ask that you think we should know about creating a program like this?

## Appendix B

### Questions for Key Informants

#### Introduction

We are designing a program to help improve the timeliness, cultural proficiency and coordination of oncology care for Denver Health providers and their Latino/a patients affected with lung and/or head-and-neck (H&N) cancers. We would like to hear your insights about what currently works and doesn't, your ideas on what might help improve the experiences of your patients with these cancer as they move through the process of care, as well as how this program could improve your ability to provide quality care to these patients.

1. Please describe your role, especially as it relates to screening, diagnosis and cancer treatment within the Denver Health system. How long have you been in that role?
2. How long have you been providing this type of care to patients? In any other settings or organizations? [If so, where else besides DH?]
3. What barriers do patients experience in accessing and receiving cancer diagnosis and treatment for lung and/or H&N cancers within Denver Health?
4. What aspects of this care work particularly well for patients in Denver Health?
5. In your opinion, what patient factors have the greatest impact on their ability to access and participate in their cancer care?
6. What causes the most difficulty for you in providing the care that you think these patients need?
7. What is particularly helpful to you as a provider?
  - team communication?
  - print materials?
  - weekly division meetings?
8. What are the holes or gaps in the overall system of oncology care at Denver Health that affect you and your patients the most?
9. What about the current system is most beneficial to you and your patients?
10. What might help improve the experiences of Denver Health cancer patients?
11. What ethnic/cultural factors play a role when working with Latino/a patients based on your experience with these patients?

12. What socioeconomic (financial or educational) factors play a role when working with Latino/a patients based on your experience with these patients?

We want to provide recommendations to design a program that is based on the concept of patient navigation, where Denver Health staff will assist patients in understanding and accessing the necessary resources within Denver Health. Besides that support, this program might include a telephone support service to provide information and decision support for patients to augment the assistance they receive from the on-site patient navigator for lung and/or H&N cancers.

13. What do you think about this idea of adding staff to reduce internal and external barriers experienced by this population?

14. How do you think these staff could help your patients?

15. What features should be included in this program?

16. What would demonstrate the program's success to you?

17. How could this patient navigator be integrated into your medical team?

## Appendix C

### Questions for Patient Navigators

#### Welcome

Hello to everyone, welcome and thank you for agreeing to be part of our focus group.

#### Introductions

First of all, let me introduce our team: I'm (name of facilitator) and this is (name of co-facilitator). Our stenographer for the evening is (\_\_\_\_)—she'll be keeping track of our discussion this evening. We're working on a project through Denver Health. The project is to provide suggestions to develop at DH a Patient Navigation program for Latino/a patients affected with lung and/or head-and-neck (H&N) cancers. So that's why we're here tonight—to get your ideas and opinions about the things you think we should include in a Patient Navigation program.

The way we look at it, YOU are the experts—you are involved in the day-to-day implementation of a Patient Navigation program for breast, prostate, and colorectum. You've been invited here tonight to give your opinion as a person who has experienced with the process of navigation at DH. We value your opinions and want you to know that what people tell us during these groups will be used to help plan this new program.

#### Ground rules

Before we begin, let me mention a few things about how we usually conduct the groups:

- 1) I will be the facilitator for the group. My role is to ask the questions we have for the group, and to encourage everyone to participate. I won't be doing much talking, but may ask you to explain more or to give an example. Also, it's my job to see that everyone has a chance to voice their opinions, as well as to keep us moving along so that we have time to discuss all of the questions. So, at times, it might seem as though I am cutting you off, and this is not meant to be rude but rather to make sure that we have time to hear from everyone on each question. Since we only have two hours, we won't have time to hear many details of each person's situation. We know that you have each been through your own experience and that sharing your experience with others can be helpful. We hope you'll understand that for these two hours we will ask you to focus on the questions asked. You can take extra time after the group is finished to talk more with each other if you wish. We want to thank each of you for being here, so please know that we value your ideas and comments.
- 2) It's really important that everyone hear this: **THERE ARE NO RIGHT OR WRONG ANSWERS!!!** Each person's experiences and opinions are valid, and we want to hear a wide range of opinions on the questions we'll be asking. So, please speak up, whether you agree or disagree with what's being said, and let us know what you think.
- 3) Sometimes participants bring up sensitive issues during these discussions, and we want to be sure that everyone agrees before we begin the group that anything of a personal nature that is mentioned in this room will **NOT** be repeated to others outside of this discussion group. Can I see a nod from everyone showing me that you agree with this confidentiality ground rule?

(If anyone is not willing to give their consent to confidentiality, they may be excused from the group.)

- 4) Let me tell you about our recording process. As you can see, \_\_\_\_\_ is here to record our discussion. We usually record these focus groups because we want to capture everything that all of you say, and we simply can't write fast enough to get it all down. We use first names only in the transcript, and when we put together the results from all the groups, we don't include any names.

It is VERY IMPORTANT that we speak ONE AT A TIME, so that (name of stenographer) can hear everything that is said. So, now that you know what our process is, is everyone OK with being recorded?

- 5) Let me mention before we start, that we plan to be finished with our discussion by (time), and then we have a brief survey for you to complete. It will take 5 minutes at the most. When you have completed the survey, we will collect the survey and at that point, you will receive the gift card as our thank-you to you for participating in our group tonight. The very last thing we need to ask of you is your signature to show that you received the incentive. Are there questions about any of this?

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### **Focus Group Questions**

8. Please tell us your first name and when you first began working at DH and whether this is your first job a patient navigator (Use calendar as a visual aid.)
9. First we're going to look back and talk about your experience here at DH from when you first starting working a patient navigator. Let's focus on this point in time, when you first learned what a patient navigator does and began working here as such.
  - Looking back, to the time when you were explained what a patient navigator does. What did you understood your role was? What were you supposed to do that was different from other staff at DH (nurses, social workers, etc)?
  - Are there things that should have been explained to you that would have made your job/role more clear to you?
    - Any particular training?
  - More time with your supervisor?
10. Now let's move ahead to the time when you had a few months to get a handle for what is expected of you as a patient navigator. Think about the time when you realize what it takes to fulfill your job and the experiences you have had since.

- Was there anything or anyone in particular that helped you understand better what it is that you are expected to do for DH patients?
  - Are there things about the way the medical team (doctors, nurses, etc) is structured or established that makes your role confusing or less clear?
  - Some things may get in the way of doing your job as you are expected to do it, what would be some examples of the obstacles that you see at DH?
  - Some things might make your job as easier or facilitate doing what you are expected to do, what would be some examples of these at DH?
  - If there was anything that you could change to be able to more easily do your job as you are expected, what would that be?
11. Think about the different times or phases that patients go through when they are in treatment, whether it is chemo, radiation, surgery, or any combination of these, what do you think helps them the most to get through their cancer treatment?
- Information
  - Transportation
  - Better access to their health care provider
  - Someone to answer their questions
  - Support and information about insurance
  - Financial resources---rent, other expenses
  - Are there things that you think could be done better for patients at DH that could particularly help them:
    - During their treatment?
    - Their family during their treatment?
    - Anything else that could help them?
  - Are there things about the medical doctor, nurse or other staff that makes it difficult for patients to get the treatment care they needed?
  - When you see that patients encounter these difficulties (mention a few examples from answers to previous questions) is there any one among the staff that you feel you can talk to or that you think you would talk to in order to remove or address difficulties and be able to better help patients?

12. These questions are specific to your experience working particularly with Latino/a patients. We would like to know if there are aspects of their cultural background, beliefs, or ways of doing things or communicating that need to be considered when they receive patient navigation services, specifically:

- How should family members be included or not in the navigation process?
- Are there some particularly inappropriate or discouraging ways of doing things or communicating that makes Latino/as distrust receiving help?
- What cultural aspects need to be understood and respected for Latino/a patients when providing services to them?
- What behaviors or ways of communicating would show respect for their culture or their people that they would like to see or receive during their treatment care?
- Should other community supports be included for some Latino/a patients, for example clergy or providers of alternative medicine (e.g., herbalist, curandero/a) to help patients cope better with their treatment?

13. We need your help in figuring out how to create a patient navigation program for Latino/a patients who have lung or head-and-neck cancers. It is okay if you do not know much about these cancers, as we need to figure out what type of training you would need to then help such patients through navigation.

- First, do you know about Lung cancer and its' treatment?
- Do you know about head-and-neck cancers and its' treatment?
- What type of training or information that you have sought have helped you to better understand a particular type of cancer and its treatment?
- In general, the treatment that lung and head-and-neck cancer patients receive tends to be more complex than those for patients with other cancers. For example, lung and head-and-neck cancer patients might have to receive help from the eye doctor, the dentist, or speech specialists. Would helping patients coordinate these services be something that a navigator could do? Is it too much and what would you need to fulfill your role?

Is there anything we've forgotten to ask that you think we should know about creating a program like this?



**Section II**

1. When were you/the patient first diagnosed with cancer? \_\_\_\_ month \_\_\_\_ year
2. What type of cancer was diagnosed?                    \_\_\_\_ Lung                    \_\_\_\_ Head-and-Neck
3. Did you/the patient have surgery?                    \_\_\_\_ Yes                    \_\_\_\_ No
4. Did you/the patient have chemotherapy?                    \_\_\_\_ Yes                    \_\_\_\_ No
5. Did you/the patient have radiation therapy?                    \_\_\_\_ Yes                    \_\_\_\_ No
6. Did you/the patient have biological therapy?                    \_\_\_\_ Yes                    \_\_\_\_ No

**Section III**

1. Do you speak----->

- |              |                             |                                       |                             |              |
|--------------|-----------------------------|---------------------------------------|-----------------------------|--------------|
| Only Spanish | Spanish better than English | Both Spanish and English equally well | English better than Spanish | Only English |
|--------------|-----------------------------|---------------------------------------|-----------------------------|--------------|

2. Do you read---->

- |              |                             |                                       |                             |              |
|--------------|-----------------------------|---------------------------------------|-----------------------------|--------------|
| Only Spanish | Spanish better than English | Both Spanish and English equally well | English better than Spanish | Only English |
|--------------|-----------------------------|---------------------------------------|-----------------------------|--------------|

3. Was your early life [childhood and teenage years] spent in---->

- |                       |                         |                                      |                   |             |
|-----------------------|-------------------------|--------------------------------------|-------------------|-------------|
| Only in Latin-America | Mostly in Latin-America | Equally in Latin-America and the USA | Mostly in the USA | Only in USA |
|-----------------------|-------------------------|--------------------------------------|-------------------|-------------|

4. Is your current circle of friends---->

- |                              |                          |   |                                      |                     |
|------------------------------|--------------------------|---|--------------------------------------|---------------------|
| Almost all Hispanics/Latinos | Mainly Hispanics/Latinos | Equally Hispanics & Non-Hispanics from the U.S.A. | Mainly Non-Hispanics from the U.S.A. | Almost all from USA |
|------------------------------|--------------------------|---|--------------------------------------|---------------------|

5. In relation to having an Hispanic/Latino background, do you feel---->

- |            |       |                |              |          |
|------------|-------|----------------|--------------|----------|
| Very Proud | Proud | Somewhat Proud | Little Pride | No Pride |
|------------|-------|----------------|--------------|----------|

## Appendix E

### Key Informant Socio-demographic Questionnaire

1. Do you consider yourself to be (check one):
  - Hispanic or Latino
  - Not Hispanic or Latino
  
2. Which of the following categories best describes you (check all that apply):
  - American Indian/Alaska Native
  - Asian
  - Native Hawaiian or other Pacific Islander
  - White
  - Black or African American
  
3. How long have you been working with Denver Health patients? \_\_\_\_\_
  
4. What is your medical specialty? \_\_\_\_\_
  
5. For MDs: What year did you finish your residency program? \_\_\_\_\_
  
6. For RNs: When did you finish nursing school or advanced practice training (i.e NP)?  
\_\_\_\_\_
  
7. Gender: Male                  Female

## Appendix F

### Patient Navigator Socio-demographic Questionnaire

1. Gender: Male \_\_\_\_\_ Female \_\_\_\_\_
2. Do you consider yourself to be (check one):
  - Hispanic or Latino
  - Not Hispanic or Latino
3. Which of the following categories best describes you (check all that apply):
  - American Indian/Alaska Native
  - Asian
  - Native Hawaiian or other Pacific Islander
  - White
  - Black or African American
4. How long have you been working with Denver Health patients? \_\_\_\_\_
5. Have you worked as a Patient Navigator before? Yes \_\_\_ No \_\_\_  
 If **yes**, where have you worked as such before? \_\_\_\_\_  
 If **yes**, for how long have you worked as Patient Navigator? \_\_\_\_\_
6. Place an 'X' in the box that best described the highest level of education you completed:

Grade School								High School				College				Post Graduate
1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	

7. Do you speak----->
 

Only Spanish	Spanish better than English	Both Spanish and English equally well	English better than Spanish	Only English
--------------	-----------------------------	---------------------------------------	-----------------------------	--------------
8. Do you read----->
 

Only Spanish	Spanish better than English	Both Spanish and English equally well	English better than Spanish	Only English
--------------	-----------------------------	---------------------------------------	-----------------------------	--------------