THESIS

CHALLENGES FACED BY LATINOS DIAGNOSED WITH LUNG AND HEAD-

AND-NECK CANCER

Submitted by

Katie L. Scott

Department of Psychology

In partial fulfillment of the requirements

For the Degree of Master of Science

Colorado State University

Fort Collins, Colorado

Spring 2010

COLORADO STATE UNIVERSITY

December 16, 2009

WE HEREBY RECOMMEND THAT THE THESIS PREPARED UNDER OUR
SUPERVISION BY KATIE SCOTT ENTITLED CHALLENGES FACED BY
LATINOS DIAGNOSED WITH LUNG AND HEAD-AND-NECK CANCER BE
ACCEPTED AS FULFILLING IN PART REQUIREMENTS FOR THE DEGREE OF
MASTER OF SCIENCE.

Committee on Graduate Work

_____
James H. Banning

_____
Ernest L. Chavez

_____
Advisor: Larry J. Bloom

_____
Co-Advisor: Evelinn A. Borrayo

_____
Department Chair: Ernest L. Chavez

ABSTRACT OF THESIS

CHALLENGES FACED BY LATINOS DIAGNOSED WITH LUNG AND

HEAD-AND-NECK CANCER

Researchers have focused on understanding the healthcare needs and psychosocial

challenges experienced by cancer patients and survivors. However, investigators have

focused less on the particular needs and challenges experienced by medically

underserved ethnic minorities who are affected by cancer. In this study, seven key

informants and four lung and five head-and-neck Latino cancer patients diagnosed at a

safety-net hospital in Denver, CO were interviewed concerning the difficulties these

patients face navigating the healthcare system as well as the patient factors that contribute

to these difficulties. The study also inquired about potential resources that might mitigate

the needs and challenges patients experience during cancer treatment. Ethnographic

Content Analysis was employed to analyze the data obtained from the interviews. The

long-term goal is to utilize this data to develop and implement a patient navigation

program for low-income Latinos diagnosed with lung and head-and-neck cancers at a

safety-net hospital in Denver, CO.

Katie L. Scott
Department of Psychology
Colorado State University
Fort Collins, CO 80523
Spring 2010

Challenges Faced by Latino Patients

The National Cancer Act of 1971 has greatly improved our understanding of the causes, prevention, detection, and treatment of cancer. However, the benefits, including increased survival rates, from this improvement have not been fully reaped by all Americans, particularly those in underserved populations. 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).

These concerning trends in the treatment of cancer in low-income Latinos are especially relevant for patients 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.

Additionally, both the morbidity and treatment of lung and head-and-neck cancers may affect the most basic functions of life, including breathing, swallowing, speaking, and the senses of smell, taste, and vision (McLane, Jones, Lydiatt, Lydiatt, & Richards, 2003; Pandey, Devi, Thomas, Kumar, Krishnan, & Ramdas, 2007). The morbidity associated with all cancer sites is great, but research indicates that the distress related to the symptoms experienced by patients diagnosed with lung cancer is greater than the distress related to other cancer sites (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001; Degner & Sloan, 1995; Weisman & Worden, 1977). Studies indicate that the most prevalent distressing symptoms experienced by lung cancer patients are fatigue, pain, cough, anorexia, and insomnia (Degner & Sloan, 1995; McCorkle & Benoliel, 1983). Additional symptoms often reported by lung cancer patients include poor outlook and dyspnea (Sarna, 1993). The treatment of lung cancer has also been shown to cause significant physical hardship to patients (Cooley, Short, & Moriarty, 2003). Research also indicates that the treatment of head-and-neck cancers have a significant effect on patients' well-being. For instance, typical treatment of this type of cancer involves surgical resection of the tumor and surrounding facial tissue, which often results in facial disfigurement and functional disability (Watt-Watson & Graydon, 1995).

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). 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 distressed sub-groups of cancer patients (Carlson et al., 2004; Zabora et al., 2001; Koster & Bergsma, 1990).

This psychological stress may also be impacted by the traumatic nature of lung and head-and-neck cancers. These types of cancers often impact essential aspects of day-to-day life, such as breathing and eating, as well as lead to long-term dysfunction and disfigurement through the process of treatment (Frampton, 2001). The potential long-term dysfunction and disfigurement experienced by these patients may also cause further 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 (Breibart & 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; Breibart, 1994).

Although there is much research available concerning the physical, emotional, and economic stressors experienced by patients diagnosed with lung and head-and-neck cancer, there is no research available specifically relating to Latinos diagnosed with these types of cancer. As discussed earlier, the impact of a cancer diagnosis is often more detrimental to Latinos as they experience worse prognoses and more difficult treatment processes (ACS, 2005; CCC, 2005). It can be assumed that this disparity will be true to Latino patients diagnosed with lung and head-and-neck cancer, but research on these patients specifically is needed both to add to the knowledge base and to begin a discussion of potential interventions to help these patients. This significant contribution was made by focusing on the responses of key informants and low-income Latino patients diagnosed with lung and head-and-neck cancer about the psycho-social, medical, and financial difficulties these patients face during their treatment journey. This focus

elucidated the factors that medical professionals and patients deem as difficult or challenging for Latino patients diagnosed with lung and head-and-neck cancers.

Additionally, this study addressed the following research questions:

1. What patient factors do health care providers perceive pose a challenge to low-income Latinos diagnosed with lung and head-and-neck cancers as they go through their treatment?

    a. Specifically, what mental health factors do health care providers perceive are particularly challenging to low-income Latino patients?

    b. What socio-cultural factors do health care providers perceive are particularly challenging to low-income Latino patients?

    c. What medical factors do health care providers perceive are particularly challenging to low-income Latino patients?

    d. What financial factors do health care providers perceive are particularly challenging to low-income Latino patients?

2. What patient factors do patients perceive pose a challenge to low-income Latino patients diagnosed with lung and head-and-neck cancers as they go through their treatment?

    a. Specifically, what mental health factors do patients perceive are particularly challenging to low-income Latino patients?

    b. What socio-cultural factors do patients perceive are particularly challenging to low-income Latino patients?

    c. What medical factors do patients perceive are particularly challenging to low-income Latino patients?

d. What financial factors do patients perceive are particularly challenging

to low-income Latino patients?

3. What social, medical, and financial resources do these patients currently rely on

to deal with the challenges they encounter as they go through their treatment?

Method

Participants

Participants in this study included 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. 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) cancer. 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. 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 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).

Procedures

This study was part of a larger study being conducted at a safety-net hospital in Denver, CO that will incorporate input from key informants, patient navigators, Latino patients diagnosed with lung and head-and-neck cancers, and their caregivers to develop a patient navigation program for Latino patients diagnosed with lung and head-and-neck

cancers. Participants were recruited from the hospital at which the patient navigation program will be implemented. This medical center is a safety net hospital located in Denver, Colorado and serves approximately 258,769 residents who reside in 32 medically-underserved areas. The individuals residing in these areas tend to be young, low-income minorities and to experience significant disparities in their health care. Patient navigation programs are currently in place at the hospital, but the current programs are for patients diagnosed with breast, prostate, and colorectal cancers. As previously discussed, these types of cancers are associated with far less complex treatment processes and far better outcomes.

An in-depth interview design was used to assess barriers, unmet needs, and lack of services for low-income Latinos diagnosed with lung and head-and-neck cancers. This design was significant to the exploratory nature of this study as it allowed for the participants to voice their opinions regarding difficulties that directly affect them as medical health professionals and patients, lending rich data to a problem that has not been systemically investigated. Further, this method also allowed for a significant focus on the participants' own ideas about the problem. This assertion is significant as the solution to the problem is something the participants are both invested in and knowledgeable about.

After receiving consent from the participant, the patient participants were asked to fill out a socio-demographic survey and the key informant participants were asked to provide information regarding their training, professional role, and institutional affiliation. The principal investigator then completed a 30-minute to one-hour long semi-structured interview with the participant. In the key informant interviews, the focus of the interviews was on the participants' opinions regarding the quality of care provided at the

hospital, the patients factors relating to their ability to access and receive care, and recommendations for a future patient navigation program for patients diagnosed with lung and head-and-neck cancers at the hospital. In the patient interviews, the focus of was on their experience accessing and receiving care at the hospital as well as their recommendations for a future patient navigation program at this hospital. The language preferred by the participant was honored, meaning that patients who were most comfortable being interviewed in English had their interviews conducted in English, and the patients who were most comfortable being interviewed in Spanish had their interviews conducted in Spanish. All interviews were audio-taped and later transcribed for analysis. Interviews continued until it became apparent that saturation had been reached, which occurred when no new information was being provided in the interviews.

Measures

The level of acculturation to the dominant United States culture of the participating patients was assessed with the General Acculturation Index (GAI) (Elder et al., 1991; Balcazar, Castro, & Krull, 1995). The GAI is a shortened version of the Acculturation Rating Scale for Mexican Americans (ARSMA) (Cuellar, Harris, & Jasso, 1980). Items on the GAI assess the use and preference of language, the location of early development, the current social network, and the pride in ethnic background through the use of a 5-item Likert-type scale that ranges from "only Spanish" to "only English." Previous use of the GAI has shown alpha reliabilities that range from .80 (Borrayo, Buki, & Feigal, 2005) to .95 (Borrayo & Jenkins, 2001). Due to a small sample size (N=9), this study did not examine the reliability of the GAI using Cronbach's alpha, but did calculate the means and standard deviations of the patients' scores on the GAI.

As previously discussed, a socio-demographic survey inquiring about participating patients' 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 each patients. Key informants provided information regarding their professional role, time in this role, institutional affiliation, and training received on another demographic survey.

Analysis

The transcripts of the recordings of the in depth interviews of key informants and patients were analyzed utilizing Ethnographic Content Analysis (Altheide, 1987) to extract 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. Additionally, efforts were made throughout the process of analysis to

maintain trustworthiness through triangulation of analysis, peer debriefing, and prolonged

engagement. The training of the research assistants began with all research assistants

analyzing the same interview transcript. Their initial analysis included individually

reading the interview 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 semi-structured interviews 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 interview 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 interview transcripts had been analyzed.

After all interview 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.

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 research study and may play a role in the interpretation of the data presented.

Results

General Acculturation Index (GAI)

The patients' level of acculturation to the dominant culture of the United States was measured using the GAI. This index inquired about language typically written and spoken, geographic location during childhood, ethnicity of friends, and degrees of one's pride in one's Hispanic background. Answers were provided on a five-point Likert scale. To obtain the index, answers were averaged. As the number increased from one to five, the level of acculturation to the dominant culture of the United States increased. The mean of this measure was .320 with a standard deviation of .667. Chronbach's alpha could not be calculated for this sample as the sample size ($N = 9$) was too small.

Ethnographic Content Analysis

In the *narrating* process of the Ethnographic Content Analysis, it was decided to merge the responses of the health care providers and patients to the first two general research questions into one to provide a more clear presentation of the results. Basically, it appeared that the responses by patients to each of these two questions were better understood in the context of the comprehensive framework that the health care providers offered.

Research Question 1 and 2: What patient factors do health care providers and patients perceive pose a challenge to low-income Latinos diagnosed with lung and head-and-neck cancers as they go through their treatment?

The information provided by the key informants and the patients regarding these challenges will be presented together but separated by the sub-questions posed within the research questions that are common to both groups.

Both key informants and patients identified several challenges affecting the treatment journeys of Latino patients diagnosed with lung and head-and-neck cancers. These factors can be broken into several large categories: mental health factors, socio-cultural factors, medical factors, and financial factors. It should be noted that the key informants endorsed more challenges than did the patients who were interviewed. This point will be addressed further in the discussion, but it may be understood within the context of exposure to the treatment journey experience. That is, the key informants seem to have more experiences to draw upon when discussing the challenges faced by their patients because they have treated various patients of these conditions throughout the years. Because of this, the explanation of the patient factors will rely primarily on the content of the key informant interviews with information gained from the patient interviews serving as further evidence.

Mental Health Factors: What mental health factors do health care providers and patients perceive are particularly challenging to low-income Latino patients?

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." The impact of cancer can change the way Latino cancer patients behave. For instance, patients may become antisocial, as illustrated by one key informant, "And it's tough to whittle on somebody's face, it really is, because you change that person. And they can become reclusive, you know, antisocial." 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." One patient expressed feeling particularly distressed by the hair loss he experienced due to his chemotherapy treatment by saying,

> "Cause when my hair felt out, I told my wife she said, 'What's wrong?' I said, 'I don't know. I think I slept on my hair funny because my hair hurts.' She said, 'Your head hurts?' I said, 'No, my hair hurts.' She said, 'How does your hair hurt?' I don't know but it hurts, and then when I went outside and it just happened to be, you know it was windy and I went like that and there it comes. But it hurt, but the hair strands hurt. And she said, 'You mean your head hurts?' 'No,' I told her, 'my hair hurts.' It was a weird feeling."

Patients were also distressed by the side effects of their treatments, and they reported not feeling well during their treatment journeys.

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?

Socio-Cultural Factors: What socio-cultural factors do health care providers and patients perceive are particularly challenging to low-income Latino patients?

Socio-cultural factors related to the patients' identities as Latinos were often discussed by the key informants. These factors included the themes that patients suggested were important values, such as emotional protection of family members and traditional health practices. With regard to emotional protection, Latino families are important and very protective of each other, which leads them to try be involved with the

treatment of a family member from the time they receive a cancer diagnosis. This issue can be difficult for health care providers as they treat Latino cancer patients.

> One of the things we run up against in the hospital is when, some of these folks, because of their culture their families don't want them to know their diagnosis. Um, or downplay their diagnosis. And that becomes difficult for us. I mean it's really difficult when we have to treat a patient with chemotherapy not to tell them that they have cancer.

Patients also discussed a desire to protect family members from the news that they had been diagnosed with cancer.

> Other patients did not want to tell their family members about their diagnoses out of concern for their loved ones, as indicated by one patient who stated, "At first I wasn't even gonna tell my kids, I was just, and then she said, my wife said no, that ain't right, what if you die, I mean, they gotta be prepared. But I was gonna try to go through it without letting anyone know."

> 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."

> 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. It is also suggested that things like alternative treatments have a place in the treatment process but that traditional medicine is also very important. For instance, one key informant stated

> I think one of the things I've heard from a lot of immigrants when we talked about surgery with lung cancer is that they don't want to have surgery because they've heard that will cause the cancer to spread. And in fact, with lung cancer the cancer may come back but I don't think the surgery causes cancer to spread. So that's one thing. I guess another thing is for some people approach medical with base thinking. That the prayer, spirituality and other approaches will actually provide physical cures. And you know I think there's a place for that but I think it's also important to get medical treatment to get the best outcome.

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 key informant,

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.

Medical Factors: What medical factors do health care providers and patients perceive

are particularly challenging to low-income Latino patients?

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 done 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 understanding what is happening with their body. 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.

Key informants assert the role patients play in adhering to their care as well as many factors that impact this adherence, such as family support, financial difficulties, miscommunication, misunderstanding, and language barriers. As explained by one key informant, "It could be financial, it could be miscommunication, not understanding the medical process, it could be language barriers." Further, Latino cancer patients have a

tendency to miss appointments due to various factors. These factors are explained by one key informant,

> Once you see the patient and they want you to do specific tests for that patient it
> takes a long time to have this test done and scheduled. It's not just that, it's
> contacting the patient back and letting them know they have an appointment. And
> sometimes they get information and sometimes they don't get information.
> Sometimes they miss appointments because they are difficult patients and
> sometimes they don't really know when the appointment was made. So I would
> say that you know, once you see the patient and you have the diagnosis and you
> explain the plan, then you might think that it would take two weeks to have it
> done, it might take probably two months. So that's the, I think, difficulty with
> head and neck cancer patients.

Additionally, some patients do not comply with recommendations from their providers and have difficulties being actively involved in their treatment. The importance of patients' active participation in their treatment is asserted by one key informant, "When they know about it, they can be a team player because they understand it. I think it helps because they're part of it."

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 came 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.

Patients discussed specific health indicators that had an impact on their treatment

journeys. Some patients had indicators for cancer, such as smoking and a family history

of cancer, while others did not. Age appeared to play a role in disease prognosis, as

younger patients seemed to have better prognoses than older patients. This point was

noted by one patient, "Dr. ## told me in the beginning that I had a lot of pluses going

because I was only 50, I was young, a lot younger than some of his patients." Other

health-related factors, such as a pacemaker, also complicated treatment. Patients dealt

with other health concerns, such as strokes, infections, and muscular-skeletal problems,

while also dealing with their cancer.

Both key informants and patients acknowledge that the "quality of

communication" between patients and their health care providers affects the success of

the care provided. Communication impacts Latino cancer patients' ability to understand

aspects of their treatment journey. This is illustrated by one key informant, "Poor

understanding, different ideas about what everyone's point view is, and establishing that

trust is important and I think it needs to be addressed." Further, it is important for health

care providers to ensure that they and the patients understand each other. Potential causes

for misunderstanding are stated by one key informant, "Um, well, some patients don't

understand what doctors say and they don't express that because they are afraid of, you

know, what the doctor is going to think of them or they think they understand but once they leave the clinic they don't understand so that's a major issue."

Financial Factors: What financial factors do health care providers and patients perceive are particularly challenging to low-income Latino patients?

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, "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."

Additionally, poor living conditions, such as over-crowding, can have an adverse effect on health in the Latino population, which can be particularly detrimental for patients suffering from cancer. This is pointed out by one key informant,

> Another huge factor is they may be living in a house that has sometimes two or three families sometimes in it. And they can get sick because you know, this kid goes to school and gets a virus and brings it home and the whole entire house has got this virus and that patient ends up being very sick because of that. And so that's very difficult for the patient.

Question 3: What social, medical, and financial resources do these patients currently rely on to deal with the challenges they encounter as they go through their treatment?

In addition to the patient factors impacting their treatment journeys, key informants and patients also discussed the resources that were available to the patients during this time. These resources included social support, spirituality, transportation assistance, emotional support, financial assistance, and information regarding their cancers and treatments.

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 assistant in decision making.

Key informants also see spirituality as a helpful factor as Latino patients go through their treatment journeys. One key informant commented on this importance by saying, "I think they're very spiritual people. I think that part of treating people has to do with spirituality, and I think that they um, have um, you know, a lot of faith. They're faith-based, which is very powerful." Patients also discussed the impact spirituality had on their treatment journeys. Many patients indicated that have a strong faith and turned to this faith while dealing with their cancer, and patients also asserted that spiritual leaders should be made available during treatment for support. In addition to spiritual leaders, patients also indicated that alternative methods, such as herbs and home remedies, should be available.

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 DHMC 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."

Key informants and patients discussed the emotional toll a cancer diagnosis and its treatment can have on a patient. Patients identified resources available to them that provided them with emotional support during these difficult times. These resources included support groups, support from survivors, support from families, support for families, and support from co-workers. Patients also indicated that receiving this support from the very beginning of their treatment journeys would have been most helpful, as asserted by one patient speaking about a support group he attended, "Yeah, it would have

been a lot more helpful in the beginning. I mean I really enjoyed it and towards the end I wasn't able to come back because of transportation problems."

Some patients felt as though they were given enough information regarding their diagnoses, treatments, and treatment side effects from their providers, while others patients were dissatisfied with the amount of information given to them and felt as though they had to pursue this information themselves. This disagreement is indicated by two dialogues between the interviewer and two different patients:

Interviewer: You feel you had enough information during treatment, like if something wasn't happening the way you thought it would happen?

Patient: Nope, it happened, just like, everything happened just the way they told me it was gonna happen.

Interviewer: Okay, did you have enough information about how to deal with side effects?

Patient: Yeah. It was real good information.

Interviewer: Did you have information about options that you had?

Patient: Mmhmm.

This is contrasted with another patient who appeared dissatisfied with the information available to them:

Interviewer: Did they give you any type of information?

Patient: No, I don't think so.

Interviewer: They just told you like they didn't give you something to read or someone to call?

Patient: No.

Interviewer: No, but you wish you would have had more?

Patient: Yeah, I do.

Interviewer: So all of the information you received was from your doctor?

Patient: Yes, from my doctor.

Interviewer: Were you able to call him if you had any questions?

Patient: No, he didn't give me his number.

Interviewer: So just when you made your appointments?

Patient: I talked to him then.

Some patients felt as though their providers gave them adequate verbal explanations of their cancers and what they could expect from their treatment. Patients also often received written information in various forms, such as books and brochures, that they felt adequately helped them understand their cancers and treatment. This written information was often provided to them by the Resource Center at DHMC, and patients were able to receive this information in Spanish. Patients also pursued information on the internet to help them understand their diagnoses and treatments. Some patients also wanted to pursue a second opinion about their diagnosis, and some patients were able to receive this information.

Discussion

Difficulties abound for Latino patients diagnosed with lung and head-and-neck cancers. These difficulties include mental health factors, socio-cultural factors, financial factors, and medical factors. Throughout their interviews, key informants displayed concern for these difficulties and discussed the ways in which these difficulties impact the treatment journeys for Latino patients diagnosed with lung and head-and-neck

cancers. It was often expressed that these challenges act as barriers to the patients receiving adequate care for their cancer, which can be significant and even deadly for patients who are in need of this care. Patients also thoughtfully discussed these challenges and offered insight from the personal experiences regarding the ways these challenges operate to impede successful treatment.

Despite these difficulties, key informants and patients were able to identify several factors in addition to resources that do help to aid in the treatment journey of Latino patients diagnosed with lung and head-and-neck cancers. These factors include spirituality, social support, and family inclusion. Patients were able to provide their personal experiences with the resources made available to them to help ameliorate the effects of the challenges they face as they navigate their treatment journeys. These resources included transportation assistance, financial assistance, emotional support, and information regarding their diagnoses, treatments, and side effects of their treatments.

It is interesting to note the difference in the perception of "challenges" faced by Latino patients diagnosed with lung and head-and-neck cancers from key informants and patients. The key informants seemed to identify many more barriers in the treatment journeys of these patients, while the patients seemed to express satisfaction with the process they have undergone. This difference may have several, intertwined explanations. First, the key informants interviewed in this study have a multitude of experiences from which to draw their opinions of the experiences Latino patients diagnosed with lung and head-and-neck cancers because of the several patients they have treated throughout the years. The key informants interviewed also have the fortunate circumstance of having higher socio-economic statuses and adequate healthcare coverage. Because of this in

addition to their training as medical health care providers, they are likely to have higher expectations of the health care system than the patients. The patients interviewed appeared appreciative of and surprised by the mere fact that they were receiving treatment in the first place and did not hold high expectations of how they "should" be treated. This is likely due to their overall lack of financial resources and specific lack of health insurance. Because they did not have the resources typically needed for health care, the patients did not expect to be provided with any care at all. Additionally, although not directly discussed within the interviews conducted in this study, it has been shown that Latinos hold ideas about illness and death that may be protective against the fear and anxiety many attribute to a cancer diagnosis. The patients interviewed in this study did express fear and anxiety regarding their cancer diagnoses, but it is possible that these protective beliefs about illness and death may have insulated the patients from frustrations with the barriers identified by the key informants.

Although the patients in this study may have been somewhat protected from frustrations with the challenges experienced throughout their treatment journeys, we do know that Latinos diagnosed with various types of cancer experience worse prognoses and more difficult treatment processes (ACS, 2005; CCC, 2005). Further, due to the poor treatment outcomes, complex courses of treatment, psychological distress, and the barriers discussed in this study, it is significant to consider and address the concerns of these patients through effective methods. Evidence has shown cancer patient navigation programs to be effective in managing the care of medically underserved cancer patients (Freeman, 2004). However, research on cancer patient navigation programs has primarily focused on patients diagnosed with breast cancer, which is a type of cancer associated

with less mortality, morbidity, and complexity of treatment (ACS, 2005). Additionally, although research on these types of programs has included ethnic minority patients, it is important to investigate the effectiveness of a culturally appropriate patient navigation program for low-income Latinos. This research focuses on these deficiencies in the literature as it serves as a significant contribution to the development of a patient navigation program for low-income Latinos diagnosed with lung and head-and-neck cancers. As explained above, this study is part of a larger study being conducted at the hospital, which is working toward the implementation of a patient navigation system for Latino patients diagnosed with lung and head-and-neck cancers.

Limitations

The limitations of this study include potential researcher bias, little emphasis on the unique contribution of socio-economic status, and heterogeneity of the sample. As previously discussed, the author holds opinions and comes from a context that may impact her interpretation and presentation of the data. Much work was put into reducing the risk of researcher bias through triangulation between research team members during the analysis process. However, it is difficult to tease out the impact of researcher bias. Additionally, this study emphasized the impact of being Latino on the treatment journeys of the patients interviewed. The patients interviewed also came from significantly low income backgrounds, and it would be interested to attempt to tease out the unique impact of a Latino identity and the unique impact of a low-income background on navigating the treatment journey of cancer. Future research should consider these unique, but often overlapping, factors. Finally, the sample included in this study was relatively heterogeneous, varying by gender, age, education, and amount of time living in the

United State. Because the experience of males and females, younger participants and older participants, individuals with more and less education, and individuals living in the United States for long and short periods of time were analyzed together, the unique experiences of these groups may have been lost. Thus, it would be beneficial for future research to consider focusing on these unique experiences.

Contributions and Future Directions

The work presented in this study addressed a dearth in the literature regarding the challenges faced by Latinos diagnosed with lung and head-and-neck cancers. Although literature is available about the stressors experienced by patients diagnosed with these types of cancer more generally, as previously discussed, there is no research available specifically focusing on Latinos diagnosed with these types of cancer. It was important to address this absence in the literature as the impact of cancer is known to often be more detrimental to Latinos as they receive worse prognoses and experience more difficult treatment journeys (ACS, 2005; CCC, 2005). Through this study, information regarding challenges specific to low-income Latinos diagnosed with lung and head-and-neck cancers can be added to the knowledge base. These challenges include the impact of Latino cultural beliefs, language differences, immigration status, poor living conditions, and lacking "health competency" and trust in health care providers.

Having an awareness of these specific challenges can allow for the implementation of interventions that address these challenges in order to provide less difficult treatment journeys for low-income Latinos diagnosed with lung and head-and-neck cancers. As part of a larger study being conducted at a safety-net hospital in Denver, CO that will incorporate the information from this study and some additional analyses to

develop an intervention, a patient navigation program for Latino patients diagnosed with lung and head-and-neck cancers. Such a patient navigation program can work to ameliorate the specific difficulties while also addressing stressors known to impact all cancer patients diagnosed, such as psychological distress and a decline in day-to-day functioning. The information provided regarding the resources currently available to these patients may allow for a good starting point from which this intervention can grow as it details the status quo of support for these patients. Additionally, while the information provided in this study will be used to develop a specific intervention for a safety-net hospital in Denver, CO, it can also be utilized more generally in understanding and developing health care programs for low-income Latino cancer patients.

It is important for future research to continue to focus on the challenges faced by low-income Latinos dealing with a lung and head-and-neck cancer diagnosis. Future research should look to delve further into the mental health concerns presented by these patients. This focus may allow for the development of interventions specific to the psychological distress these patients experience and the best manner of delivery of these interventions. Future research should also examine factors related to the delivery of medical treatment, such as time from diagnosis to treatment, and their impact on both the physical and emotional well-being of these patients. More research should also be done to address the "health competency" of these patients and ways to address this lack of knowledge. Additionally, future research should consider utilizing a larger number of participants and incorporating other minority populations that have not specifically been addressed in the literature.

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