University of Cincinnati

Date: 6/16/2017

I, Taylor M. Walker, hereby submit this original work as part of the requirements for the degree of Master of Arts in Communication.

It is entitled:

Student’s name:       Taylor M. Walker

This work and its defense approved by:

Committee chair: Shaunak Sastry, Ph.D.

Committee member: Pamara Chang

Committee member: Heather Zoller, Ph.D.
Abstract: This project takes an ethnographic approach to understanding how third party patient navigators challenge, negotiate, construct, and constitute their role within the navigation process. This study examined a local nonprofit organization, the Cancer Justice Network, as it compares and contrasts to the traditional model of navigation. Results showed that patient navigators have the potential to influence the success of the navigation process based on the communicative strategies used. Additionally, this study examined the extent to which the Cancer Justice Network utilizes a culture-centered approach to healthcare.

Keywords: Patient Navigation, Ethnography, Listing, Disclosure, Culture-Centered Approach
Acknowledgements

The completion of this project would not have been possible without the help of many, to name a few:

I would like to express my upmost gratitude to my advisor, Dr. Shaunak Sastry for his continuous guidance and support throughout the course of the research project. I am incredibly thankful for the assistance and encouragement of my committee members, Dr. Heather Zoller and Dr. Pamara Chang. I am beyond grateful that my advisor and two committee members were more than willing to lend a helping hand and provide support every step of the way. I owe a great deal of appreciation to my fellow graduate students for helping me survive the stress of graduate school through their positivity and reassurance when I needed it the most. Finally, I am humbled and honored to be allowed to work with and follow the Cancer Justice Network over the last year; as well as be able to participate with the navigators throughout their journey.
# Table of Contents

**Introduction** .................................................................1  
**Chapter 1** .................................................................3  
  Literature Review ......................................................3  
  Methodology ............................................................22  
**Chapter 2** .................................................................26  
  Results .................................................................26  
**Chapter 3** .................................................................51  
  Discussion ..............................................................51  
  References ..............................................................56
Rationale

I have always been interested in understanding the perceptions associated with cancer, and in particular, the lived experiences of those undergoing a cancer diagnosis or treatment. Since moving to Cincinnati, I have been presented the opportunity to work with an organization that aims to help underrepresented cancer patients through the process of patient navigation. While patient navigation has been embraced by the biomedical community, there is little to no communication research that explores the communicative dynamics of patient navigation. The Cancer Justice Network’s efforts towards developing a navigation program in Cincinnati represented a good opportunity for me to document firsthand how communication is present—or absent—from the conceptualization and implementation of navigation programs.

Introduction

This research study explores the role of third party “patient navigators” in shaping the communication dynamics between health providers and patients. Patient navigation is an established process through which trained community members (navigators) guide at-risk individuals from their community through the complexity of the healthcare system. Patient navigation has been found to be very effective in improving cancer outcomes in populations that face significant health disparities (Freeman, 2004). The project uses an ethnographic approach towards understanding the “best practices” of a navigation relationship, by observing how a local non-profit organization (Cancer Justice Network) trains volunteer navigators, and how those navigators in turn communicate with potential patients. Hamilton County experiences some of the worst disparities in cancer outcomes in the state of Ohio, with racial disparities in cancer mortality being nearly twice as high for African-Americans as it is for Whites (National Cancer Institute). Echoing national trends, cancer outcomes in this region are strongly associated with
socioeconomic status, with an overall negative correlation between socioeconomic status and a host of cancer-related outcomes, like mortality, access to preventive screenings, treatment etc (Boeshart, T., Carlson, D., Davidson, C.S., Lordo, K.L., Samet, M.J.,2015).

The Cancer Justice Network (Cincinnati, OH) is based on the Ralph Lauren Patient Navigator Program (New York City, NY) developed by Harold Freeman, MD. In 1989, the American Cancer Society conducted hearings aimed at understanding cancer treatment disparities. The report found a number of findings: 1) the poor are under resourced and have significant barriers during diagnosis and when seeking treatment, 2) external sacrifices often have to be considered by the poor before obtaining cancer care, 3) the poor are often not diagnosed until incurable stages of the disease, and 4) A fatalistic attitude is prevalent among the poor and prevents them from obtaining cancer care. After these findings, the first patient navigation program, the Freeman study in Harlem, New York, was developed and as a result increased both hospitals and the government’s commitment to supporting patient navigation programs (Wells, K. J., Battaglia, T. A., Dudley, D. J., Garcia, R., Greene, A., Calhoun, E., 2008). The impact of the first Patient Navigator Program was significant. Before access to cancer screening and patient navigation, low income cancer patients had a 39% 5 year survival rate (Freeman, 2003). After access to cancer screening and patient navigation, low-income cancer patients enrolled in the navigation program had a 70% 5 year survival rate (Freeman, 2003). Patient navigation, therefore, has potential to change cancer survival rates by providing patients with opportunities to combat the social, logistical, economic and cultural barriers to cancer care.

The primary contribution of this project is to document what existing navigators believe is most central to the success of a navigation relationship. Here, we draw from the impetus of navigation research (Freeman, 2004ab; 2006, 2008, 2012), listening research, and culture-
centered research projects (Dutta et al, 2016) and focus on documenting the voices of communities and community partners as they work together in overcoming institutional challenges to health. Through the testimonials of community members currently engaged in patient navigation, along with an analysis of existing research, and written documents about navigation, this project adds to the understanding of “best practices” for navigation. The rationale here is that enhancing the quality of the navigation process will in turn enhance the quality of community-based health interventions in area of cancer.

**Literature Review**

The literature relating to patient navigation and this research project can be divided into three major sections. First, literature concerning patient navigation, primarily focusing on Freeman’s work. Second, literature focused on interpersonal health communication and patient centered care. Third, literature focused on culture centered approaches to health.

**Patient Navigation and the Freeman Approach**

The concept of Patient Navigation has been pioneered by Harold Freeman, M.D., and was introduced because in the United States, African-American patients have the highest cancer mortality rates (Freeman, Muth, & Kerner 1995). This is in part due to higher incidences in specific areas of the country but largely the result of late-stage diagnosis in minorities as compared to non-minorities (Freeman, Muth, & Kerner, 1995). In order to understand these health disparities the first patient navigation program was proposed along with an emphasis on cancer screenings in inner-city public hospitals. In the first years of this programs development (1990-1992), 1034 females and 102 males were screened for cancer (Freeman, Muth, & Kerner, 1995). The research by Freeman, Muth and Kerner (1994) demonstrated that patient navigators
were more likely to see patients with suspicious findings than patients with non-suspicious findings. Additionally, 70% of patients with suspicious findings were not seen by a patient navigator (Freeman, Muth, & Kerner, 1995). However, 87.5% of patients who were seen by a navigator, completed recommended breast biopsies, compared to the 56.6% of the non-navigated patients (Freeman, Muth, & Kerner, 1995), exemplifying the effectiveness of using navigators. This baseline research demonstrated the need for a consistent patient navigation program with trained patient navigators as a mode to reduce cancer disparities among minorities.

Freeman (2004b), argued that there is a critical disconnect between, “what we discover and what we deliver,” meaning there is a gap in policy creation versus implementation and enforcement, education versus understanding, and knowledge versus action. Understanding this divide, Freeman researched policies and interventions enacted by the United States government, the National Cancer Institute (NCI), the American Cancer Society (ACS), the Center for Disease Control (CDC), the Institute of Medicine (IOM), as well as poverty, culture, and social injustice in order to understand the social determinants of cancer disparities. Freeman found that residents of lower socioeconomic counties have higher cancer mortality rates, irrespective of race (2004b). However, when viewed separately each racial and ethnic group demonstrated that those living in poorer counties had lower cancer survival rates (Freeman, 2004b). Though poverty is the dominant issue, cancer disparities are caused by a complex combination of low socioeconomic status, culture, and social injustice (Freeman, 2004b). Moreover, there is evidence that race is a determining factor in the level of healthcare received; many studies suggest that the racial and ethnic bias of medical providers and patient bias influence the quality of health care delivered (Freeman, 2004b; Street, R. L., 2003; Fiscella, K., Franks, P., Gold, M. R., Clancy, C. M., 2000). Furthermore, current as well as historical racial injustice is one of the determinants of cancer
disparities creating disconnect between prevention, diagnosis, and treatment of cancer (Freeman, 2004b). Freeman took these findings and provided various recommendations for change and reducing the cancer disparity among those in impoverished areas; three of which are significant to the present study.

First, medical coverage should be provided for those who are uninsured and/or underinsured upon a diagnosis of cancer to guarantee that no person with cancer goes untreated (Freeman, 2004b). Second, areas with excessive cancer mortality rates should concentrate their approach to, “providing culturally relevant education, appropriate access to screening, diagnosis, treatment, and an improved social support network” (Freeman, 2004b). And most importantly, these communities should receive funding for Patient Navigator Programs, which will eliminate any barriers to patients obtaining timely and adequate cancer diagnosis and treatment (Freeman, 2004b). These recommendations demonstrate how navigation programs should conduct their services (i.e. being culturally relevant and providing a social network for patients) and what outcome can be obtained through this process. Mainly, the implementation of patient navigation programs increases the likelihood for success in increasing cancer outcomes for low income and minority individuals.

The first Patient Navigation program in Harlem New York, operated with the testimonies of poor Americans who had been diagnosed with cancer, from a Freeman lead ACS study, as the basis for the program (Freeman, 2004a; Freeman, 2006; Vargas, Ryan, Jackson, Rodriguez, & Freeman, 2008; Freeman, 2012). Freeman found that, “Poor people meet significant barriers when they attempt to seek diagnosis and treatment of cancer. Poor people and their families make sacrifices in order to obtain cancer care and often do not seek care because of barriers faced. Poor people experience more pain, suffering, and death because of late diagnosis and
treatment at an incurable stage of the disease. Fatalism about cancer is prevalent among the poor and prevents them from seeking care.” (Freeman, 2004a; 2006; 2012). According to Freeman, in order to reduce cancer mortality rates three steps should be taken. First, provide education and outreach programs (Freeman, 2004a; 2006). Second, provide access to examinations, which includes screenings (Freeman, 2004a; 2006). Third, ensure that any patient with a cancer positive finding with receive further diagnosis and treatment (Freeman, 2004a; 2006). Freeman (2004a; 2006, 2012) highlights that there are many barriers a patient may experience throughout cancer diagnosis and treatment including financial barriers, communication and information barriers, medical system barriers, and psychological and emotional barriers. Patient Navigation is intended to eliminate barriers to diagnosis and treatment through one-on-one contact with the patient beginning at the point of a positive cancer finding (Freeman, 2004a; Freeman, 2006; Vargas, et al., 2008; Freeman 2012). Freeman states that patient navigators should be, “1) Culturally attuned to the people of the community being served, able to communicate, be sensitive and compassionate; 2) Very knowledgeable about the environment and system through which the patient must move in order to obtain care; and 3) Highly connected and allied with critical decision makers within the system, especially with the financial decision makers” (2004a). Utilizing patient navigators with the mentioned characteristics and the step-by-step process to reduce cancer disparities the Harlem study yielded interesting results. Before access to cancer screening and patient navigation, low income cancer patients had a 39% 5-year survival rate (Freeman, 2004a). After access to cancer screening and patient navigation, low income cancer patients had a 70% 5-year survival rate (Freeman, 2004a). Freeman attributes these successes to the center offering free and low-cost screening, rather than the navigation
relationship itself, which allowed for early diagnosis. The Patient Navigation program promoted treatment with no delay as well as the improved outreach and public education (2004a).

Freeman has documented the key principles that define the process of patient navigation. First, patient navigation is a “patient-centric healthcare service delivery model” (Freeman, 2011). This means that the focus of patient navigation is patient-centered, where navigators help patients from their community through the healthcare system (diagnosis, treatment, and survivorship). Second, patient navigation serves to “virtually integrate a fragmented healthcare system for the individual patient” (Freeman, 2011). Since patient-centered approaches to healthcare focus on the timely movement through the healthcare system, patient navigators are often help create a continuous flow through a sometimes segmented system. For example, sometimes there is a gap between when a diagnosis is made and when treatment begins. This gap can be attributed to multiple factors: availability or finances. Patient navigators are able to close or eliminate this gap by providing access to financial help, aiding the patient in their interactions with doctors and the medical system, and by arranging transportation for patients. Third, a core function of patient navigation is the “elimination of barriers to timely care across all segments of the healthcare continuum” (Freeman, 2011), carried out through developed one-on-one relationships between navigators and patients. The relationships built between the navigators and the patients to which they serve allow for the process of navigation to be carried out. Navigators understand what each patient needs and develop a plan specific to that patient. Fourth, patient navigation should be “defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers” (Freeman, 2011). This is significant because roles and responsibilities of the navigator are clearly defined to the navigator and to the patient. Additionally, navigators are integrated into the healthcare team in order to
provide the maximum care possible for each patient (2011). By having navigators already established as a part of the healthcare team, navigators are already at the patients’ disposal and can begin navigating from the patients’ first appointment through the end of care. Fifth, the delivery of patient navigation services should be “cost-effective and commensurate with the training and skills necessary to navigate an individual through a particular phase of the care continuum” (Freeman, 2011). In short, the process of patient navigation should be cost-effective for the patient as well as organization. Traditionally, navigators are paid; navigator training and procedures are clearly defined and developed in order for navigation services to be efficient for the patient and cost-effective for the organization. Moreover, patient navigators should receive training and demonstrate skills that reflect their role within the organization and that best allow them to traverse patients through a cancer diagnosis. Sixth, the determination of who should navigate should be “determined by the level of skills required at a given phase of navigation” (Freeman, 2011). Patient navigation is a spectrum ranging from trained navigators to professional navigators to other various healthcare professions. Each tier of navigation is characterized by training, skills, and qualifications. It is significant that every navigator knows their level and only provides navigational care according to that level. For example, navigators who are trained both as navigators but also have medical training are able to provide medical advice to the patients which they are serving. While navigators who are trained but do not have advanced medical training are only permitted to eliminate barriers not provide medical advice. Seventh, in a healthcare system “there is the need to define the point at which navigation begins and the point at which navigation ends” (Freeman, 2011). Eighth, patient navigation takes place “across disconnected systems of care, such as primary care sites and tertiary care sites” (Freeman, 2011). Patient navigation differs from a traditional healthcare experience because
navigation takes place at various points in care including community events, screening sites, hospitals and offices, and other healthcare sites. Lastly, Patient Navigation systems require coordination (Freeman, 2011). A Patient Navigation system is the overarching model where patient navigation takes place. It is significant to distinguish between the system and those participating within the system. Freeman (2011) suggests that there should be a patient navigator coordinator who oversees all aspects of the navigation system.

Since its inception in Harlem, patient navigation has been seen as an effective community-based intervention and widely studied within medical and science fields. Meade, Wells, Arevalo, Calcano, Rivera, Sarmiento, and Roetzheim (2014) recount experiences, challenges, and lessons that occurred while implementing a patient navigator program to improve cancer care among underserved patients. While according to Freeman patients have challenges associated with financial, emotional, psychological and physical barriers (2004ab, 2006, 2012), navigators have challenges with language barriers; familiarity of communities the navigators served; provision of training, education, and supportive activities; multidisciplinary clinical oversights; and well-developed partnerships with community clinics and social service entities (Wells et al., 2014). Additionally, Paskett, Harrop, and Wells (2011) aimed to build on Freeman’s work by reviewing studies on navigation that support Freeman’s findings as well as develop evidence regarding the benefit of patient navigation in diagnostic follow-ups and navigation within in the treatment settings. Review showed that there was no direct correlation between patient navigation in diagnostic follow-ups or in treatment settings (Paskett, Harrop, & Wells, 2011). A criticism of patient navigation is that it cannot be translated to other health disparities. Wang, Gallivan, Lemon, Borg, Ramirez, Figueroa, Rosal (2015) however, have built on patient navigation literature by taking it outside of a cancer context. The study found that
when diagnosing and treating a chronic illness in a community health center, “77.8% [of patients] scheduled an appointment through the Patient Navigator. These patients had higher rates of visits [with a primary care physician] 6 months post-call (90%)” (Wang et al., 2015). This demonstrates that patient navigation can be translated outside of the cancer context.

Understanding that there was a definitive gap between obtaining cancer care to finding an abnormality and then to diagnosis and treatment, research from the Harlem patient navigation project was used to develop the Harold P. Freeman Patient Navigation Institute (HPFPNI) and a model for patient navigation (Harold P. Freeman Patient Navigation Institute, 2017). In 2007, funded by the Amgen Foundation, the Ralph Lauren Center for Cancer Care and Prevention founded the Harold P. Freeman Patient Navigation Institute with the intention of establishing the standards and best practices of patient navigation (Harold P. Freeman Patient Navigation Institute, 2017). The core principles of the Patient Navigation institute are: (1) Educate potential patients about the necessity for cancer examinations and provide timely access to such examinations; (2) Eliminate any barriers to timely access to cancer examinations; and (3) Eliminate barriers to diagnosis and treatment in cases where an abnormality is found (Harold P. Freeman Patient Navigation Institute, 2017). The Patient Navigation Institute is considered the quintessential embodiment of patient navigation and is guided by two main goals. First, to uphold standards for patient navigation programs by emphasizing the Harold P. Freeman Patient Navigation Model (Harold P. Freeman Patient Navigation Institute, 2017). Second, to help other navigation programs learn best practices by guaranteeing that programs follow to the “peer-reviewed, recognized definition and measures for patient navigation set forth by the Patient Navigation Research Program” (Harold P. Freeman Patient Navigation Institute, 2017).
The Patient Navigation model provides a pathway for intervention. This model operates under the assumption that there is a critical timeframe between the point of detection and the point of resolution where patient navigation can be applied in order to eliminate barriers to care (Harold P. Freeman Patient Navigation Institute, 2017). The current model (figure 1) demonstrates the movement of a patient across the entire healthcare continuum.

Figure 1: The Freeman model of patient navigation (From Freeman et al, 2011)

This model is multidimensional, in that it outlines the breadth and depth of patient navigation. As shown in Figure 1, at the micro level patient navigation begins at the point of an abnormal finding or during outreach efforts and is then continued throughout the course of care to rehabilitation or resolution. This in turn affects the macro level of navigation; cancer prevention
influences survival and mortality when patient navigation is utilized throughout the care continuum.

The Patient Navigation Model is then emphasized as the gold standard in patient navigation and is utilized during the Harold P. Freeman Patient Navigation Institute Patient Navigation Program, as the ideal approach to navigation that can be adopted and adapted to other navigation programs. The HPFPNI program is a two-day training program that includes: 10 navigation modules, a practicum in patient interaction, and case studies in patient navigation (Harold P. Freeman Patient Navigation Institute, 2017). The HPFPNI curriculum is multi-faceted, comprehensive, and interactive; including practical experience that reflects best practice research and theoretical information gathered by experts in patient navigation (Harold P. Freeman Patient Navigation Institute, 2017). The program supports an increase in retention, diagnostic, and treatment resolution rates and improved organizational efficiency (Harold P. Freeman Patient Navigation Institute, 2017).

This model and program utilize patient navigators or paid, trained team members that, “provide one-on-one guidance and assistance to individuals as they move through the health care continuum from prevention to end-of-life care.” (Harold P. Freeman Patient Navigation Institute, 2017). Patient navigators function as a liaison between the patient and the healthcare system. Navigators are responsible for eliminating barriers to timely screening, diagnosis, treatment, and supportive care for each patient (Harold P. Freeman Patient Navigation Institute, 2017). According to the Patient Navigation Institute (2017), patient navigators have a broad range of qualifications, all having varying degrees of education; however, the navigators assigned roles are determined by their levels of training, experience, and education (2017). Moreover, the HPFPNI stresses that patient navigators must be compassionate, intelligent, have communication
skills, as well as be culturally sensitive (2017) due to their involvement in all areas of the health continuum.

Patient navigation research has been predominately conducted within the medical paradigm with little to no communication research in the area. The above literature provides a comprehensive insight into the process and dynamics of patient navigation including the foundational model and how medical and science research has built, reviewed, assessed, and applied this model. Although this literature provides perspective into what has been accomplished in the area of patient navigation it has also highlighted a discrepancy. Patient navigation has yet to be studied in-depth from a communicative standpoint. My research adds to the literature on patient navigation by documenting communicative aspects associated with this type of intervention and allowing further research outside of the medical sciences, making patient navigation an interdisciplinary area of study.

**Disclosure, Listening, and Patient-Centered Communication**

Patient navigation at the core is a patient centered health interaction; it is in the interpersonal exchanges, between the navigator and the patient, where the “best practices” and “how to” of navigation are constructed, challenged, and negotiated. These tensions can be best explained by considering social sharing and appraisal-based models concerning disclosure and information-sharing.

Individuals face a variety of social and personal challenges when diagnosed with an illness; one of which is how to manage personal or private health information (Greene, Magsamen-Conrad, Venetis, Checton, Bagdasarov, & Banerjee, 2012; Derlega, Metts, Petronio, & Margulis, 1993; Petronio, 2002). Much of the research on disclosure and information sharing
has been focused on uncertainty and the Disclosure-Decision Making Model (DD-MM). The DD-MM argues that people base their decision to disclose information on evaluation of three factors: information assessments, receiver assessments, and disclosure efficacy (Greene et. al, 2012).

In the DD-MM the first factor, information assessments, is concerned with five features: stigma, prognosis, symptoms, preparation, and relevance. Stigma, an informational component widely discussed in the context of health (Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Herek, Capitanio, & Widaman, 2002), is expected to decrease patients intentions to disclose information; however, it is unclear if stigma solely reduces disclose or if anticipated reactions and efficacy influence disclosure (Greene et. al, 2012). Prognosis is a second factor that influences disclosure, specifically considering if the disease or illness is treatable versus terminal (Greene et. al, 2012). Likewise, Symptoms and disease progression are also evaluated as part of information assessment and likelihood of disclosure (Greene et. al, 2012). The preparation for diagnosis also contributes to information assessments, particularly if the diagnosis is anticipated or unexpected (Greene et. al, 2012). The final information assessment is if the diagnosis directly or indirectly affects others, or relevance. Individuals are more likely to disclose their health diagnosis if it can affect others, specifically if the disease is transmittable or genetically linked (Greene et al., 2012; Greene, 2009). Information assessments are not the only factor that contributes to disclosure. The second factor, receiver assessments, is concerned with relationship quality, anticipated reactions, and confidence in the response. Often, better relationships are associated with positive perceptions of anticipated responses (Greene et al., 2012; Afifi & Olson, 2005; Greene et al., 2009; Petronio, 2002; Vangelisti, Caughlin, & Timmerman, 2001).

Concerning relationship quality, individuals often choose to disclose information to others to
which they feel “close” and they believe they can trust (Greene et al., 2012; Greene, 2009; Petronio, 2002). Anticipated reactions also influence disclosure. Greene et al. (2009) conceptualized anticipated reactions in two main categories: the anticipated response (i.e., how support is enacted) and the anticipated outcome (i.e., will there be consequences in the relationship). The third feature of receiver assessments is the confidence in the response. Disclosure and the confidence in the response is related to the certainty to which the discloser is assured that the receiver will respond to the information in the way that the discloser anticipates (Greene et al., 2012). The more certain in how the receiver will respond, correlates to the likelihood that the disclosure feels more prepared to share information (Greene et al., 2012). The final factor, disclosure efficacy, is concerned with disclosure efficacy. Unlike other efficacy models, the DD-MM defines that both confidence and communicative skills are necessary to health information disclosure (Greene et al., 2012). Disclosure models demonstrate that individuals who have more confidence in their ability to share the diagnosis were also more likely to disclose information (Afifi & Steuber, 2009; Greene et al., 2009; Green et al., 2012).

In addition to the DD-MM and literature on how disclosure happens the Disclosure Process Model (DPM) examines when and why disclosure is beneficial. The DPM emphasizes the impact of five main mechanisms to disclosure: antecedent goals, the disclosure event itself, mediating processes, outcomes, and a feedback loop (Chaudoir & Fisher, 2010). DPM suggests that disclosure is multifaceted; disclosure can affect individual, dyadic, and social contextual outcomes through three types of processes: (1) alleviation of inhibition, (2) social support, and (3) changes in social information (Chaudoir & Fisher, 2010). One key aspect of DPM is how disclosure is conceptualized. The DPM framework defines disclosure to, “situations in which a discloser verbally reveals information to a confidant about the discloser's concealable
stigmatized identity, information that was not previously known by the confidant” (Chaudoir & Fisher, 2010).

Though the literature on disclosure is extensive in both depth and breadth, the majority of studies focus on patient disclosure directly to doctors, family, friends and those to whom they have close relationships, with little focus on third party members. This study aims to utilize disclosure literature as a framework to analyze third party patient conversations, specifically concerning the development of the observation guide.

Listening is regarded as a central component within a healthcare interaction because listening is essential for gathering data, diagnosis, and treatment choice (Jagosh, Boudreau, Steinert, MacDonald & Ingram, 2011). Listening is also a determinant in patient satisfaction (Brown, Butow, Henman, Dunn, Boyle, & Taterstall, 2002; Wanzer, Booth-Butterfield, & Gruber, 2004). Listening is a contextual process by which individuals receive, construct meaning, and respond to spoken and/or nonverbal messages (Arnold, Coran, & Koropeckyj-Cox, 2016). Two types of listening provide the groundwork for all listening subtypes: discriminative listening and comprehensive listening (Wolvin & Coakley, 1996; Welch & Mickelson, 2013). Arnold, Coran and Koropeckyj-Cox (2016) define discriminative listening as, “the most basic form”, of listening; which, “focuses on the different sounds that are produced and the nonverbal characteristics of the message but does not involve the comprehension of words or phrases” (p. 2). While comprehensive listening involves, “the understanding and retention of vocalized messages” (Arnold, Coran, & Koropeckyj-Cox, 2016; Wolvin & Coakley, 1996). Discriminative and comprehensive listening are the two major kinds of listening; however, there are subtypes of listening: therapeutic, critical, and empathic listening (Arnold, Coran, & Koropeckyj-Cox, 2016).
Therapeutic listening is when a physician wants to have “a sympathetic ear” and may require diagnostic responses (Arnold, Coran, & Koropeckyj-Cox, 2016). This type of listening demonstrates and promotes empathy which, is key to patient-centered and culturally competent care (Arnold, Coran, & Koropeckyj-Cox, 2016). When engaging in therapeutic listening, a clinicians use a supportive rather than defensive communication style, demonstrate attending behaviors (nodding or vocalized representations of understanding), and engage in note taking and/or committing the messages to memory. (Wolvin & Coakley, 1996; Coran, & Hagen, 2012; Delbene, 2015; Arnold, Coran, & Koropeckyj-Cox, 2016). Critical listening is when listeners evaluate and respond to a message (Arnold, Coran, & Koropeckyj-Cox, 2016). Providers use this type of listening when they are required to make a decision, form an opinion and/or solve a problem (Wolvin & Coakley, 1996). Empathic listening requires the listener to understand the feelings and emotions of the speaker and to respond with appropriate attending behaviors and acknowledge the patient’s feelings (Suchman, Markakis, Beckman, & Frankel, 1997). Listening offers an opening for interrogating inequalities among the distribution of power, by attending to the unvoiced assumptions and values underlying the concentration of power in the hands of the elite (Dutta, 2014).

Though listening has been documented as an important aspect to successful healthcare, the process is often regarded as a “natural” component of communication, without an understanding or recognition of the specific components and skills involved (Arnold, Coran, & Koropeckyj-Cox, 2016). The present scope of literature focuses on how listening is a part of the patient-provider interaction with little to no focus on third party roles in listening and understanding. This study will build upon the present literature in order to examine how listening and disclosure plays a significant role in third party health interactions.
Culture-Centered Approach

The practice of patient navigation draws upon facets of interpersonal communication, and it follows that listening and disclosure become relevant to the quality of the interaction between the community and the navigator. The philosophy of patient navigation (or at the very least, the philosophy of navigation embodied by the Cancer Justice Network), however, involves reckoning with larger societal and political issues regarding health, including, but not limited to how agency and power are reflected in the health care system.

Current and historical racial injustice is one of the determining factors concerning cancer disparities, which creates disconnect between prevention, diagnosis, and treatment of cancer (Freeman, 2004b). This disconnect has caused Patient Navigation systems to be developed in areas with excessive cancer mortality rates through an approach of, “providing culturally relevant education, appropriate access to screening, diagnosis, treatment, and an improved social support network” (Freeman, 2004b). This foundational principle situates patient navigation with the culture-centered approach paradigm. The culture-centered approach (CCA) aims to co-create spaces of listening and understanding in communities by providing populations who are politically, socially, and/or geographically disconnected from the hegemonic power structure a discursive platform that is rooted in the lived experiences of that population (Dutta, 2008; Dutta, 2011; Dutta, Mandal, Kaur, Pitaloka, Pandi, Tan, & Sastry, 2016). Dutta (2008) argues that, “Acknowledging the erasures from dominant discursive sites in civil society, academic, and policy spaces serves as the basis for culture centered projects that are directed at co-creating infrastructures for recognition and representation of subaltern voices” (Dutta et al., 2016). The culture centered method therefore, is a dynamic process in which dialogue, participation, and voice can be designated into dominant structures in order to expunge subaltern participation
(Dutta et al., 2016). Culture-centered approach proposes that communication operates at the juncture of culture, structure and agency (Dutta, 2008; Dutta et al., 2016). CCA differs from traditional approaches to community-based problem solving in three major facets. First, members of the community are regarded as experts regarding the cultural and communicative aspects of their communities (Dutta et al., 2016). Second, community leaders work with experts to form a dissemination strategy and tools they can access, which help guide the creation of a diverse strategy that meets their neighborhood’s needs (Dutta et al., 2016). Third, ownership and ideas are not the product of experts or outsiders who lack credibility among members of the underserved community, rather they are local (Dutta et al., 2016). It is in this relationship the ability to foster collaborative spaces and create community capacities for community based decision-making (Dutta, 2008, 2014; Dutta & Basu, 2007b; Dutta et al., 2016).

The culture-centered approach draws upon the key ideas of participation, partnerships, communication, and reflexivity. First, the CCA uses community-based participatory strategies for addressing healthcare disparities by emphasizing the principal role of the community; through an examination and categorization of the specific health problem as well as the corresponding health solutions (Airhihenbuwa, 1995; Airhihenbuwa & Obregon, 2000; Basu & Dutta, 2009; Campbell & Gillies, 2001; Campbell & Jovchelovitch, 2000; Dutta-Bergman, 2004a, 2004b; Dutta, 2008; Dutta et al., 2016; Kreps, 2005; Viswanathan et al., 2004). The community itself is the central focus of participation and neighborhoods, community centers, and community organizations play an integral part in solution development. The key aspect of the CCA is on, “creating processes, strategies, and spaces through which local voices can play an important role in developing community-specific solutions” (Baker & Motton, 2005; Dutta, 2008; Dutta et al., 2016; Ford & Yep, 2003). Participation is key because it develops a
partnership with the local community, which offers an opportunity to understand a particular health issue from the perspective of the community (Dutta et al., 2016). Partnership are the second key factor in the CCA. The CCA consist of, “the creation of community-academic partnerships that facilitate the participation of the local community in the definition of problems and solutions and in the generation of knowledge” (Dutta et al., 2016). Although similar to the culture sensitivity approach, a key factor in partnership within the CCA is that the locus of expertise and knowledge is situated within the local community (Dutta, 2007; Dutta & DeSouza, 2008; Dutta et al., 2016). Community based health interventions are most successful when expertise and knowledge is situated within the community coupled with clinically based or expert knowledge concerning the intervention (Dutta, 2007; Dutta & DeSouza, 2008; Dutta et al., 2016). Though CCA shares similarities with community-based participatory research (CBPR), however CCA differs from CBPR because the primary emphasis in CCA the community is the principle source of knowledge (Dutta et al., 2016). The CCA involves, “the creation of dynamic spaces for knowledge sharing, and collaboration and decision-making at the community level, building on the various resources (knowledge, technology, networks, etc.) brought to the table by the academic partners” (Dutta et al., 2016). Meaning, communication is created within the interactions of the community depending on the resources and knowledge contributed through the communicative aspects by those in the community as well as the experts. Culture-centered approaches are “cyclical, iterative, and dynamic” (Dutta et al., 2016) that involves 9 key processes which include: “1) Identifying and selecting community partners; 2) Developing communication processes for participation, collaboration, and decision-making; 3) Identification of community-specific needs and corresponding research problems guided by community involvement, community participation, and community dialogue; 4) Developing
communication processes, resources, and strategies for creating community-specific solutions; 5) Developing research methodology built upon community and academic partnerships; 6) Implementing the community-based, community-driven health solutions; 7) Analyzing and interpreting data; 8) Disseminating the results; and 9) Establishing community structures and processes for sustaining the CCA-based solutions” (Dutta et al., 2016). These processes allow for dialogue, the key methodological instrument used in CCA (Dutta et al., 2016). Additionally, reflexivity is a central aspect to CCA. Dutta (2008) explains that reflexivity is a process of interrogation where, “examining the sites of power and attending to the ways in which power is unevenly distributed in communities, and between academics and communities (Dutta, 2008; Dutta et al., 2016).

In order to understand how the traditional model of patient navigation, disclosure, listening and the culture-centered approach apply to the Cancer Justice Network the following research questions guided this study:

RQ1: How are the roles of a patient navigator defined by the organization (CNJ)?

RQ1a: What roles, ideals, and processes are stressed as important communicative criteria in the patient navigation process?

RQ1b: What do the defined roles, ideals, and processes by the CJN communicate about patient navigation?

RQ2: How are CCA concepts (agency and structure) communicated to the navigators through the CJN?

RQ3: How are the “best practices” of patient navigation communicated and negotiated by local-community based patient navigators within the Cancer Justice Network.
Methodology

This study uses an ethnographic approach to explore how the role of a navigator is constructed, constituted, negotiated and challenged within the cancer justice network. The construction and negation of best practices of navigation are examined in two major facets: textual analysis and participant observation.

Research Setting

Between the months of September, 2016 and April, 2017 I gathered data (i.e. navigation training materials and observation notes) as I worked alongside the Cancer Justice Network and their patient navigators. The primary set of textual materials was gathered during the navigator training sessions, yet as new materials were given to the navigators the corpus grew. Observations took place at three main locations: Christ Church Cathedral, Churches Active in Northside (CAIN), and Madisonville Education and Assistance Center (MEAC). Figure 2, shows a breakdown of the number of at-risk community members at each location.

(Figure 2)

<table>
<thead>
<tr>
<th>Location</th>
<th>Average # of Community Members</th>
<th>Average # of Navigators present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Christ Church Cathedral</td>
<td>200-300 at-risk individuals</td>
<td>2-5 patient navigators</td>
</tr>
<tr>
<td>CAIN</td>
<td>100-150 at-risk individuals</td>
<td>2-5 patient navigators</td>
</tr>
<tr>
<td>MEAC</td>
<td>50-100 at-risk individuals</td>
<td>2-5 patient navigators</td>
</tr>
</tbody>
</table>

Each navigation location operated similarly. Often the navigator administrators would do a brief talk (10-20 minutes) about the organization, about cancer in general, and about the importance of screening and early diagnosis. Meanwhile, the community members are sat at tables, generally
consisting of 6-10 individuals, and given dinner. Then the navigators were given the opportunity to go to each table and attempt to build a navigation relationship and communicate their role to the community. I followed the navigators from table to table and observed their conversations utilizing a “navigation observation guide” (see appendix A).

Textual Analysis

Often the interworking meanings or underlying assumptions of a group or organization and the processes that shape them may be, “ambiguous, invisible, and, perhaps, unknowable” (Charmaz, 2006, p. 39). However, an in-depth investigation of the texts can help reveal those meanings, assumptions and processes (Charmaz, 2006). In order to understand the communities into which the patient navigators are situated, each navigator was exposed to a detailed training guide as well as the guidelines Freeman outlined as the ideal best practices of a patient navigation experience. This study examines the training guide and navigation materials as they compare to Freeman’s framework in order to see how these texts shape the role of a patient navigator as defined by the patient navigator. The 48 pages of textual materials include the navigation training manual given to the navigators during the initial training session, printed documents and articles given to the navigators by the organization, and the screening intake forms used by the navigators. I examined the patient navigation training guide and navigation materials as free flowing chunks of text, as defined by Ryan and Bernard (2000). The corpus of text is a compilation of 48 pages of print materials gathered throughout the course of the study and examined in its entirety using a grounded theory approach. This involved a line-by-line close reading of the texts, carefully considered actions, processes, assumptions, and consequences (Ryan and Bernard, 2000). This line-by-line examination of the text derived a set of themes used for the groundwork of the coding scheme. The line-by-line reading of the texts illuminated what
the CJN emphasized as important to their mission, navigator procedures and processed, structural and cultural implications to consider, and interpersonal aspects of navigation. These major themes were then divided into smaller codes and used for analysis, including but not limited to definitional statements, role and requirement statements, and character/persona statements. Using codes as tags, to mark off text in a corpus for later retrieval or indexing (Ryan and Bernard, 2000), it is important to consider that the developed codes are not associated with any fixed units of text but are rather samples of phrases, concepts, and paragraphs across multiple pages of text (Ryan and Bernard, 2000). Concerned with the communication and negotiation of best practices of patient navigation the iterative process of grounded theory was used to analyze the coded texts in order to link to larger theoretical models. Through a constant comparative analysis and memoing as developed by Corbin and Straus (1990) data was refined and reconstructed as well as examined in relation to all emergent themes. This constant comparison was necessary to ensure that the messages developed by the Cancer Justice Network were being accurately described and examined throughout the entirety of the study. A concept map (Appendix A) was then developed to display major themes and their relationships.

**Participant Observation**

In order to understand the role and communicative dimensions of patient navigation on a deeper level, participant observation at the community events was utilized in order gain insights. This portion of the research study is an examination of the conversations had at each event. As the researcher, I took an active role in patient navigation by participating in training, as well as community dinners.

My observations were guided by a “participant observation guide” (Appendix A). This guide helped steer the observation to be focused on how the navigators communicate their role to
the local community in connection to the CJN, how the navigators perform the act of navigation, and how the navigators interact with the local community through their non-verbal communication. This guide was developed during the constant comparative analysis refinement of the data. From September, 2016 until February, 2017 analysis of the interactions were recorded as ethnographic notes during the interaction. In March, 2017 I examined my notes and developed a guide that had reflected the main themes that emerged from that corpus of collected data. These categories included: how patient navigators introduce themselves and the CJN, how the conversation incorporated navigation, the closing of the conversation, and the nonverbal communication of the patient navigator. This observation checklist was then used from March until May for the remainder of data collection.

As on observer, I followed each patient navigator and co-navigated at each of the patient navigation interactions. However, instead of filling out the same sheet as the navigator, I observed their process and filled out the observation guide. In addition, I was present before and after each navigation session to debrief with the navigators about their struggles, uncertainties, and successes. At the pre-navigation meetings I took detailed notes on questions the navigators had, the process of what was going to happen that day as defined by *John and any other conversations as they pertained to patient navigation. At the post-navigation meetings I took detailed notes on the reflections, questions, concerns, and comments made by the navigators as they pertained to their experience at the navigator training session. Grounded theory was used to analyze the corpus of data in order to link to larger theoretical models. Through a constant comparative analysis as developed by Corbin and Straus (1990) data was refined and reconstructed as well as examined in relation to all emergent themes.
Results

Textual Analysis

As mentioned, the Harold P. Freeman Patient Navigation Institute has created a working model for successful patient navigation centered on navigators. To review, the HPFPNI defines patient navigators as paid, trained team members that, “provide one-on-one guidance and assistance to individuals as they move through the health care continuum from prevention to end-of-life care” (Harold P. Freeman Patient Navigation Institute, 2017). Patient navigators function as a liaison between the patient and the healthcare system. Navigators are responsible for eliminating barriers to timely screening, diagnosis, treatment, and supportive care for each patient (Harold P. Freeman Patient Navigation Institute, 2017). Though there is no one type of patient navigator the HPFPNI suggests that navigators be compassionate, intelligent, have communication skills, as well as be culturally sensitive (2017). Despite being a clear definition of a navigator, it is also understood that navigation is a contextual process and can be adapted. This portion of the study examines how patient navigation is adapted in the CJN compared to the traditional navigation model. Additionally, the textual analysis explores how the Cancer Justice Network, as an organization, involves aspects of CCA within a patient navigation model.

The Role of a CJN Navigator. A first coding of the texts revealed three primary categories of information: 1) Defining a patient navigator, 2) Communicating the role and goals of a navigator roles and goals, (3) Communicating issues of structure and agency in cancer prevention

Definition of a Navigator. According to the CJN, a patient navigator is a, “trained representative who volunteers to help low income and minorities overcome the barriers of cancer care”. In comparison to the traditional model the two definitions are similar in they are focused on
guidance and assistance throughout the scope of healthcare, specifically concerning healthcare barriers. However, there is one distinct difference in the definitions that has a potential impact on the navigation model: paid navigators versus volunteers.

The difference in definitions between the two models is that the Freeman model uses paid representatives while the CJN is currently based on the efforts of unpaid volunteers. There are both drawbacks and benefits for using unpaid volunteers rather than paid representatives. The first drawback is that the scope of work for unpaid volunteers is significantly less substantial than for paid staff (Cherrington, Ayala, Elder, Arredondo, Fouad, & Scarinci, 2010). For example, a paid navigator has the resources to fill out and file in-take forms, organize transportation, screenings, treatment, and/or conduct follow-up meetings with multiple patients; while an unpaid volunteer may only have the resources to fill out and file in-take forms. Although this may seem superficial, it has the potential to impact the patient navigation model because more volunteers are required in order to cover the scope of work needed to conduct successful navigations. The second drawback is concerned with issues regarding flexibility. The term flexibility accounts, “the number of hours or time of day volunteers are able to participate, but also relates to the inherent ebb and flow of volunteers’ engagement/enthusiasm” (Cherrington et al., 2010). In terms of time, paid workers have more time to devote to navigation because it is their job; while unpaid volunteers must account for their schedule, the organizations schedule, and the patient’s schedules. This may influence the patient navigation model because it creates uncertainty in the number of navigators who are going to be present to navigate. When an organization relies on volunteers there is no certainty on the number of volunteers who will come to community events or meetings, the number of volunteers who will perform navigation tasks, or even the number of navigators the organization will have on any given day. This lack of
presence poses a potential problem to the model because there is no accountability for showing up and doing navigation; which, further creates a barrier to care. In terms of engagement and enthusiasm, there are times when engagement and enthusiasm are affected life circumstances. For example, a volunteer might have come to a navigation event after being laid off from their job, resulting in a lack of enthusiasm. This engagement and enthusiasm may influence the navigator’s ability to navigate. This in turn may alter the navigation model because the willingness of the navigators can lead successful navigation. The final drawback deals with support and compensation. In terms of volunteer models, “funding is needed to support infrastructure and administration, as well as incentives and other non-monetary forms of compensation given that volunteer commitment may be related to the level of support and recognition they receive from staff and affiliated organizations” (Cherrington et al., 2010); unlike in paid models that are more concerned with, “agreed upon roles, standardized training, and certification put in place so that more permanent funding may be secured” (Cherrington et al., 2010). This can influence the navigation model because organizational time and energy needs to be spent on assuring the volunteers that their time is valued and respected in order to prevent drop out rather than being focused on a cohesive program with strict rules and guidelines.

Despite the drawbacks to the definition posed by the CJN, there is a benefit. Without the rules and constraints that accompany a paid representative, volunteers are able to tailor and create experiences that directly reflect the priorities of the community (Cherrington et al., 2010). This binary may impact the navigation model because it has the potential for the navigators to identify and eliminate barriers that may not be apparent, to co-construct the navigation process with the patient, and to listen to the voices of the community to which they are serving. This benefit is directly illuminated throughout the texts. Once of such examples is a “roadmap for
citizens,” which demonstrates the pathway a navigator can guide a patient through during the navigation process. However, the next page of texts provides a list of potential barriers and describes that using a navigator would allow for quality care. These two samples imply that using a patient navigator is a collaborative process, between the navigator and patient, which is confronted through a series of steps. Another sample from the texts regarding the do’s and do not’s of navigation state, “recognize some people’s vulnerability and create a warm, accepting, and caring space for people to learn about cancer. Taking time to review is important”. This reflects the idea that the ability to tailor conversations that relate to and reflect the concerns of the patient are important. In understanding and recognizing that some people fear a cancer diagnosis the navigator can provide resources to reduce fear (a potential barrier) and further create a space for navigation to occur. Even though the definitions of the CJN and Freeman model differ, the text also reveal differences in role and requirements for navigators.

**Roles and Requirements of Patient Navigators.** Within the traditional Freeman model of navigation, the role of the navigator is to function as a liaison between the patient and the healthcare system. Navigators are responsible for eliminating barriers to timely screening, diagnosis, treatment, and supportive care for each patient (Harold P. Freeman Patient Navigation Institute, 2017). In order to eliminate potential barriers to healthcare, Freeman states that patient navigators should be, “1) Culturally attuned to the people of the community being served, able to communicate, be sensitive and compassionate; 2) Very knowledgeable about the environment and system through which the patient must move in order to obtain care; and 3) Highly connected and allied with critical decision makers within the system, especially with the financial decision makers” (2004a). Thus the role of the navigator is clearly defined in the Freeman model as a representative who uses resources to eliminate potential barriers to
healthcare. For example, if a patient is having trouble with obtaining transportation; it is the role of the navigator to arrange or help the patient receive suitable transportation.

Within the CJN, the role of a navigators is to be a support system to someone entering the healthcare system by, “(1) accompanying them the exams, screenings, treatment and/or meetings (2) helping patients obtain insurance, (3) helping with transportation barriers, and (4) providing cancer education”. Within the training guide, the CJN states that navigators have nine responsibilities in their navigation role, “(1) make sure patients who have suspicious findings get follow-up care, (2) identify barriers to care, (3) streamline appointments and paperwork, (4) assist with filling out financial forms, (5) communicate and coordinate services with patients and caregivers, (6) assist in getting culturally appropriate care, (7) connect patients with follow-up services, (8) connect patients to community and national services, and (9) keep in contact with the patient”. Understanding the responsibilities defined by the CJN, the role of patient navigator can be broken down into assist in providing education and assist in providing care.

First, the roles of a navigator in association with providing education. Within the Freeman model there is no distinction between educational roles and healthcare roles, the only role is to eliminate barriers. However, the CJN clearly articulates in their materials that navigators must both educate and eliminate barriers. CJN navigators are “required to bring American Cancer Society brochures and Cross Road Information to all navigation events to give to the community members”. This differs from the traditional model because navigation is being transformed from a patient-centered model to provide access to healthcare within an already established system to a health intervention, which promotes education and care for individuals who are entering the healthcare system. This is a significant difference between the two models. Since the Freeman model is an established organization, which works directly with hospitals and
patients registered to those institutions, education about disease and illness is inapt. The patients being served by the Freeman Institute are already established, attuned and adapted to the healthcare system. However, the CJN operates outside of the system, with a goal of “supporting those who are entering the healthcare system”. Education is an important component of the CJN model because the organization and navigators must explain their role in helping the community, how they can help, and why screening and care is important. Without education, the community has no context to why or how the CJN navigators can help eliminate barriers to care. Despite the importance of education, there is a potential concern in having an educational focus in the navigation process. When navigators play the role of educator they are likely to impose, directly or indirectly, certain health beliefs and the beliefs of the organization onto the community to which they are serving with little to no regard to the actual barriers the community faces. This is cause for concern because the CJN navigators are attempting to establish new patients into the healthcare system. When barriers are undisclosed there is a potential for those who need care to be overlooked.

Furthermore, the CJN states that navigators should, “affirm that cancer is serious because cancer is a cell that is growing without regulation and, if unexamined and untreated, in time it can kill a person. People should have exams to find out if the cancer has just started or whether cancer is growing.” When navigators are required to educate on what cancer is and why screenings are important they are stepping away from the traditional model and becoming focused on health promotion. This transition has the potential for navigators to streamline their navigation processes to “do you know about cancer” instead of “how can I help you obtain cancer care”. Additionally, this educational component creates a contradiction within the role of a navigator, under the CJN framework. The CJN states that patient navigators are prevented from
giving any medical advice or opinion to patients; yet, are asked to reaffirm the danger of cancer, the benefits of screening, and why treatment is necessary. This has an unrealized point of concern for role of CJN navigators. For example, if a navigator is asked. “I have a lump on my leg, do you think I should get screened for cancer?” The navigator is required to both to affirm that cancer is a problem that should be addressed without providing medical advice on what the patient should do. This has the potential for navigators to be uncertain on the steps they should take as a navigator and what the direct course of action should be. The capability, in this case, is not uncertainty in their understanding of how to navigate but how to properly navigate without providing medical advice or opinions. Although there is a seemingly significant contradiction, this does not determine a lack of ability to negotiate this scenario by the navigators. Next, I discuss the roles of a navigator in terms of providing care.

The second part of a navigator role is concerned with providing healthcare. Within this category the role of the navigator reflects the traditional model of navigation, specifically how navigators can eliminate barriers to healthcare. The CJN navigator is focused on eliminating economic and societal barriers to healthcare. For example, if a patient wants to sign up for a screening at an event with those resources the navigator can assist the patient in filling out forms, scheduling an appointment, and anticipate any transportation issues. The texts clearly articulate how navigators can provide healthcare and eliminate barriers simultaneously. One sample states, “I am a FREE service, OPTIONAL, and willing to accompany you and help with transportation, insurance, and meeting with doctors.” This excerpt from a section of the texts titled “Meeting with People”, describes that a navigator should explain that they are willing and available to help the patient in anything associated with obtaining care. This sample also describes that the navigator already understands barriers (costs, transportation, finding doctors,
etc.) the patient faces and can help eliminate those barriers. Additional sections of the texts describe, “I can accompany you to Crossroad Health Center in Over-the-Rhine, or to a Cincinnati Health Center, or to a pink ribbon scanning site…if you don’t have a doctor, I can accompany you to one of our doctors”. This excerpt illustrates the resources and availability a navigator has in helping a patient obtain care, specifically indicating that it does not matter if the patient has a doctor or not. A final section of the text that further explains the navigational role to providing healthcare, “if you want to sign up for an exam tonight, I can introduce you to someone from Crossroad Health Center and assist in signing up [for an appointment]”. This verifies that not only are navigators able to assist in obtaining care, but the organization has the resources to allow for navigators and patients to begin navigating the health system.

The texts corroborate that the Cancer Justice Network has both similarities and differences to the traditional model of navigation, which have the potential to influence the process of navigation. The corpus of materials also indicate that elements of a culture-centered approach to understanding health and subaltern voices is also present.

**Communicating Issues of Structure and Agency.** The Cancer Justice Network deals with large societal and political issues; mainly, how agency and power are reflected in the health care system. This portion of the textual analysis focuses on how macro issues of structure and agency are communicated to the navigators by the CJN. The CJN plays a significant role in this process by defining and illuminating structural inequalities and providing a pathway for change. The texts focus on two major structural barriers to healthcare: (1) Racial and socioeconomic related cancer mortality rates and (2) Transportation barriers.

**Racial and Socioeconomic Related Cancer Mortality.** One primary goal of the CJN is to, “change the mortality of these populations [low income and minority] in Cincinnati from having
the highest mortality due to cancer”. The CJN explicitly informs its navigators about cancer mortality in the Cincinnati area concerning the population which they are serving. Between 2008 and 2012, the National Cancer Institute and the Center for Disease Control conducted a trend period examination for state cancer profiles and found that the mortality rate (per 100,000) in Hamilton County, Ohio was roughly 372 whites and 474 minorities; a difference of over 100 residents. In addition to the issues surrounding race and socioeconomic inequality, the CJN also communicates structural barriers to transportation within the texts. This is relevant because of its attempt to change the conversation around cancer from an individualist appeal to a social change frame. Rather than persuade individuals that preventing/treating cancer is exclusively a matter of making effective healthcare choices, CJN realizes that informing people of the social and structural roots of cancer disparity is the starting point for engineering participation in the healthcare system for those that are disenchanted by it.

Transportation Barriers. Although the texts do not explicitly state that there is a barrier to transportation, the focus on how to provide transportation and on how to communicate that transportation accommodations can be made, indicate that transportation poses a significant threat to the community the CJN is serving. The text materials indicated various forms of transportation available to the community and how navigators can assist. One of which ways is insurance or governmental assistance when paying for transportation. The “transportation form” within the navigator training guide states that, “a patient, a neighbor, or a friend may drive a person to their appointment and be reimbursed through Medicaid [if Medicaid eligible]”, or “insurance can pay for transportation and patients should ask a navigator for assistance.” This demonstrates structural inequalities pertaining to having or being Medicaid or insurance eligible to obtain transportation. Often, the community members the CJN is serving are uninsured, which
prevents them from having reliable transportation and/or obtaining care. The CJN has attempted to combat this structural barrier through their partnership with Molina Insurance. Molina Insurance offers uninsured patients free health insurance. Importantly, Molina Insurance representatives are present at all community events, allowing for navigators to work with the patient and insurance representative to provide insurance to those in need and combat needs for transportation.

In addition to governmental or insurance assistance to paying for transportation, the CJN also contests transportation barriers through alternative routes. The texts illuminate that without insurance, transportation to and from appointments is still achievable. One way includes utilizing the Chris Collinsworth ProScan which, according to the texts, will “pick up and return a person home after screening for breast cancer.” This is significant because it eliminates uncertainty surrounding getting to and from a screening but also eliminates uncertainty as to where screenings take place. Even without insurance a patient can get screened and enter the healthcare system. Another method utilized to prevent transportation barriers demonstrated in the texts is, “using [the] Cincinnati Metro Bus with tokens provided by the organization.” This is an act of eliminating transportation barriers by the CJN because the organization understands that some patients may be willing to use public transportation to get to medical appointments but cannot afford to do so. By providing bus tokens, the CJN is enabling care by providing a reliable method of transportation.

By understanding that transportation barriers are a key structural influence that affect low-income, at-risk community members from entering the healthcare system the CJN has engaged in one level of the culture-centered approach. Although important, structure is not the only facet of the CCA that is reflected by the CJN. The texts also revealed the use of partnership
and agency. Partnership are a key factor in the CCA. The CCA states that, “the creation of community-academic partnerships that facilitate the participation of the local community in the definition of problems and solutions and in the generation of knowledge” (Dutta et al., 2016), are significant to the success of the project. The CJN focuses significantly on their partnerships within the texts as a means to, “provide cancer education, connect to a navigator, meet a physician, access transportation, and obtain additional resources. The texts revealed that partnerships were concentrated to Church Partnerships, Healthcare Partnerships, and to academic partnerships.

The first category of partnerships includes those with local churches: Christ Church Cathedral, Churches Active in Northside (CAIN), and Madisonville Education and Assistance Center (MEAC). The texts demonstrate that these partnerships will allow the CJN to service approximately 150-200 individuals at each event. This is significant to the goal of the CJN because it allows them to reach a wide number of people whom may not be established in the medical system. Furthermore, the texts state, “the CJN will present cancer information during the meals and seek to connect navigators to people interested in early screening, transportation, and connecting to healthcare centers. This is noteworthy because it demonstrates a key element of the CCA by the CJN—mainly, going into the community and facilitating dialogue surrounding concerns of the community to which they are partnered. The texts focus on navigators’ communication with the community members (i.e. discussing transportation options, education on early detection, etc.). This act of participation by the navigators allows for the voices of the community to be heard and understood—which, ultimately should allow for the CJN and other partners to adequately serve the community.
The second category of partnerships includes healthcare organizations: the Cincinnati Health Department, the American Cancer Society (ACS), and the Crossroad Health Center. The texts focus on education and screenings. For example. The Crossroad Health Center is partnered with the CJN by, “physicians working with patient navigators to assist in transportation and support for treatment.” Crossroad Health Center is a key partnership for the CJN because they allow for patients to work with a navigator and a physician. This is crucial to the CJN’s goal of reducing cancer mortality because it allocates a medical facility for low-income, at-risk, and/or minority patients to obtain care. With this partnership the CJN has the potential to educate the community about cancer as well as enter those patients into the medical system. The partnership with Crossroad Health Center provides a location for services while the ACS provides other benefits. The ACS will, “provide materials for all CJN meetings that relate to cancer, early screening, and treatment. They will also assist with transportation information and support of transportation.” This partnership is significant because it allows for the distribution of materials to educate as well as provides transportation assistance. When navigators are communicating with the community they are able to understand the questions, concerns, and uncertainty each individual faces. The partnership with the ACS can eliminate some questions surrounding cancer, screening, and transportation because the navigators have print materials (brochures and pamphlets) that explain those processes. This denotes the benefit of partnerships within the CCA framework; in that a navigator listens to and understands the voices of the community (i.e. questions surrounding screening procedures), the CJN communicates this to their partner, the ACS, and the ACS provided the CJN and navigators materials regarding screening processes to take back to the community. These partnerships with healthcare organizations play a significant
role in processes and day-to-day activities conducted by the CJN but are not the only significant partnership.

The third category of partnerships includes academic partnerships. The CCA involves, “the creation of dynamic spaces for knowledge sharing, and collaboration and decision-making at the community level, building on the various resources (knowledge, technology, networks, etc.) brought to the table by the academic partners” (Dutta et al., 2016). The texts uncover that academic partnerships will, “recruit navigators, hold training conferences, and provide opportunities for evaluation.” Within a CCA, the CJN is seemingly utilizing academic partners to train and evaluate navigators, whom are at the core of the community-level discursive spaces.

The academic partnerships, as indicated from the text expert earlier, are responsible for providing the navigators with the training and knowledge necessary to co-create spaces for collaboration and decision-making within the community based on the available resources.

**Participant Observation**

As defined by the CJN, a navigator is a trained representative who volunteers to help low income and minorities overcome the barriers of cancer care. Generally, navigators are responsible for accompanying patients to exams, screenings, treatment and/or meetings; helping patients obtain insurance; helping with transportation barriers; and providing cancer education. Considering the fluidity of this definition, this portion of the study was guided by the primary research question:

**RQ: How are the “best practices” of navigation communicated and negotiated by local-community based patient navigators within the Cancer Justice Network?**
The communication and negotiation used by the patient navigators can be best understood by examining each part of the patient navigation encounter: opening conversations, the navigation conversation, ending conversations, and the navigators’ presence.

**Opening Conversations**

The observations during the opening conversations were guided by three primary questions, “Did the navigator introduce themselves?”, “Did the navigator talk about the CJN?”, and “Did the navigator explain their role?” Navigators chose to construct opening conversations in various ways, which influenced how best practices were seen as being negotiated and communicated.

The first aspect of negotiation demonstrated by the navigators was in the opening conversation concerning the questions, “Did the navigator introduce themselves?” and “Did the navigator explain their role?” Navigators determined whether it was important to introduce themselves or not to the community to which they served. This simple act of introduction has important communicative criteria in establishing “best practices”, operating under the assumption that “best practices” reflect the definition, roles and responsibilities defined by the organization. Introductions varied into three major categories: (1) none at all, (2) personal introduction but not to their role as a navigator, and (3) personal and organizational introductions.

When opening the conversation, navigators were often brought to the tables the community members were eating at and asked to begin the navigation process. However, it was completely up to the navigator to determine the best course for beginning the navigation process. Some navigators chose to not introduce themselves or their role as a navigator at all. These
conversations often began with questions, such as, “Have you been examined for cancer?” or “Do you need a cancer screening?” Although, these seem beneficial and relevant to the mission—there is no context for the community to which the navigators are trying to serve. This may communicate a power difference and potentially takes the interpersonal relationship out of the interaction. In this context, the “best practices” of navigation are not based on either the Freeman model or the CJN model of navigation, but rather imply a significance of signing people up for screenings. Once such navigator began the conversation with, “Does anyone want to have a screening?” This opening line was met with confused looks from the community members and several members saying, “no” or “I’m not interested”.

This has potential implications for the navigation process. When there is a lack of relationship building, patients are less likely to disclose information and concerns (Chaudoir & Fisher, 2010). This affects the navigation process because community members who may need navigator help may be less likely to avail that help from the navigator. Furthermore, when there is a dismissal of introductions and a jump to screening—there is no context provided to the community, to how the navigators can help community members or why navigators are there to help. Since the CJN is focused on entering people into the medical system, there is an emphasis “signing up”, with some disregard to the relational aspects of navigation (i.e. listening and disclosure).

Often navigators who use the introductory approach of asking questions regarding to screenings or doctors, without introducing themselves, were heard saying, “how many people have we [the CJN] signed up today” or “Did we sign up enough people?” This is indicative that these navigators have negotiated the concept of “best practices”. In this category of introductions the negotiation of “best practices” seems to revolve around providing community members the
initial step into entering the healthcare system with the major barrier being “obtaining an appointment for screening”. These navigators are seemingly communicating that navigation is mainly signing up people for screenings and being a navigator during the initial process of entering the healthcare system. However, some navigators do not follow this method of opening conversations but chose to introduce themselves. These navigators fit into the second category of introductions and focused on more relationship building.

The second category of introductions is associated with navigators that chose to introduce themselves but not their role or the organization. These conversations began with, “Hi, I am *Betty. Do you mind if I sit and talk to with today?” or “Hello, my name is *Michelle. How are you doing today?” These navigators accomplish “best practices” of navigation in terms of beginning to build a relationship with the community to which they are serving.

Many of these navigators remarked that, “the community trusts them [navigators] and enjoys having conversations when they [navigators] come to events”. This is a central development in the negotiation of “best practices”. A concern with if the community remembers and trusts the navigators is communicated by this category of navigator. One such navigator often opens conversations with, “Hi, I am *Sue. Do you mind if I chat with you today about?” Often this category of navigator was encouraged to sit and talk with the community members and asked, “what are you doing here today?” which sparked the conversation. This not only indicated agency and interest from the community members but also suggests that relationship building is central to the navigation process. This category of navigator, who tended to be more relationship focused, was often heard talking about specific interactions they had with community members or seen being approached by community members. This is significant to the navigation model because when the community trusts navigators, the community members
are more likely to listen to educational information, disclose health information, or communicate with their navigator about struggles obtaining healthcare. This open communication between the two parties allows for potential barriers to healthcare to be easily identified and prevented. The “best practices” of navigation are communicated as more than “signing people up” but rather forming relationships with the community and signing people up/educating them about cancer.

Some navigators tended to focus on community members with which they already had relationships with, stating, “there is *George and *Rachel, from the last dinner. I am going to go see how they are doing?” This presents both a risk and an additional layer of negotiation. A crucial aspect to maintaining relationship is to continue conversation and disclosure. Likewise it plays a significant role in the navigation process. These navigators indicate that “best practices” involve continued communication with the community members. However, there is also a potential risk. When there is too much focus on certain community members, some members may be ignored or forgotten. One example of this is a navigator who spent an entire navigation session at a table with community members whom she said, “these are my friends from church”. This navigator had introduced themselves to the table but realized they already had prior relationships with certain community members. Since this navigator chose to focus on those individuals, it is likely that some community members were not afforded the opportunities connected to navigation. When there is an over focus on preexisting relationships, new relationships are harder to be formed; thus, allowing for some community members to not receive navigation opportunities, a lack of disclosure to occur and ultimately affect the success of the CJN navigation model. A third category of navigator, embodies a deeper negotiation of navigation.
The third category of introductions is associated with navigators who introduce themselves and the organization. Often, these conversations are, “Hello, my name is *James and I am a patient navigator with the Cancer Justice Network. Does anyone have any questions about cancer or screenings or is there anything I can help you with as a community navigator?” This is the gold standard of CJN navigator introductions and clearly communicates the role and “best practices” of a navigator. Often, navigators using this approach to introductions were met with smiles and welcomed to their tables to discuss more about cancer or the organization. Furthermore, navigators who utilized this approach to introducing themselves were often privy to community conversations. Community members would often follow this introduction with responses such as, “Hi, I am Kenneth. I have been experiencing pain and wanting to get a screening. Can you help me with that?” These navigators build on the communicative dimensions of “best practices” displayed by the other navigators by incorporating what they do, mainly navigate. By adding where they work and what their role is, these navigators were able to achieve the most initial disclosure among navigators. These navigators indicate that “best practices” include not only relational aspects but professional aspects regarding the organization.

However it is important to note that specifics of their role (i.e. their responsibilities as a navigator had no impact on reception during opening conversations. For example, some navigators in this category of introduction chose to open with, “Hi, my name is *Jean and I am a patient navigator with the Cancer Justice Network. I can assist in helping with transportation, insurance, or signing up for a screening. Do you mind if I sit and talk with you?” While, some navigators in this category chose to say, “Hello, my name is *James and I am a patient navigator with the Cancer Justice Network. Does anyone have any questions about cancer or screenings or is there anything I can help you with as a community navigator?” Regardless, of which approach
this category of navigators took, the reaction from the community was generally the same. This means that being explicit in the responsibilities of the navigator role was not deemed necessary communicative criteria by the community. Meaning, the community members often disclosed the same information if the navigator described who they were and their role of being a navigator with little regard to the specific details of the navigator roles and requirements. In turn, navigators then decided whether it fit in their spiel or not. Once the navigators had negotiated how to open the conversation, they moved to conversations surrounding navigation itself.

**The Navigation Conversation**

The observations during the navigation conversations were guided by six primary questions, “Did the navigator answer medical questions?,” “Did the navigator know how to answer questions?,” “Did the conversation seem forced by the navigator?,” “Did the navigator try to connect with the patients?,” “when did the navigator fill out the intake form?,” and “Did the navigator handle lack of knowledge from the patient well?” Navigators chose to construct navigation conversations in various ways, which influenced how best practices were seen as being negotiated and communicated. The second category of conversation and opportunity for negotiation demonstrated by the navigators was in the conversations surrounding the navigation process. The act of how navigators actually “navigated” patients and how they accomplished the navigation itself, has important communicative criteria in establishing “best practices”. The process of navigation conversations centered on various aspects, including but not limited to: answering medical questions, understanding and relating to the patients, and filling out patient in-take forms.

The first aspect that shaped the “best practices” of navigation dealt with answering medical questions and knowing how to answer community member questions. This is significant
because within the CJN model, navigators are not trained medical practitioners and, therefore, are not permitted to provide medical advice in any capacity. However, in the traditional model, medical practitioners or healthcare workers have the potential to be navigators and their navigator roles reflect that medical training.

Within the CJN role, navigators chose to explain to the patients in various ways the questions/comments they could answer versus those they could not. Often, the navigators would simply state, “I am not permitted to answer medical questions”; which, in fact, is accurate but also has the potential to shut down the conversation. Navigators who used this method to explain that they could not answer the community members question were often met with silence or the same question restated. This indicates that navigators using this approach are communicating one of two “best practice” attributes the community. The first, is the navigator and/or the organization may not be able help them, which is denoted by silence. The second, is navigator did not understand what the community member was asking. This reveals that navigators need to be more explicit in their responses or explain why they cannot answer questions (i.e. they are not permitted or they did not understand).

However, some navigators were both direct and relational in their responses to their ability to answer medical questions. One example of this is, “I cannot answer medical questions or give medical advice, but I can help find someone who can. Would you like me to do that for you?” This statement, is considered the gold standard for what a navigator should say when confronted with medical questions. Often navigators were met with approval and interest in learning more from a medical doctor or additional questions of clarification. Questions of clarification included, “how much will it cost?” or “do I need to go somewhere else to do that?” This method allows the navigator to describe their role and that they are not permitted by the
organization to answer certain questions but also continues the developed relationship with the patient to whom they are helping. Additionally, it reinforces the idea that a navigator is available to help eliminate any barrier to healthcare the patient may come across. Within this section of the navigation conversation communicative criteria and negotiation also occurred when navigators attempted to answer community members’ non-medical questions.

Generally, navigators chose to respond to community member questions by using knowledge of procedures outlined by the organization and training guide or by informing the community member they would find out for them. These conversations often were centered on statements such as, “That is a great question, I currently do not know the answer but I will find out as soon as possible and let you know.” This communicates to the community member that a navigator will attempt to understand and eliminate barriers to obtaining care, even when they initially do not know the next steps. More often than not, the navigators were approached with medical questions, questions not outlined in the training materials, or questions that needed more clarification from CJN administration; this required the navigators to highly consider how they communicated their role as a navigator and how they can help the community without deterring the community members from obtaining care. Navigators also had to negotiate when to fill out in-take forms and relationship building.

The second aspect of role negotiation by navigators is associated with understanding and relating to the patients. Here navigators determined whether rapport building was central to their role as a navigator. Some navigators chose to focus their conversations solely on filling out the in-take form, rather than talking to and answering patient questions. Navigators using this communicative strategy would solely answer questions on the in-take form and ignored questions such as, “how much will this cost?” or “I do not know if I want to see a doctor, does
that matter?” Within this strategy, navigators are communicating to the community members that their role as a navigator is to first fill out the form and then answer specific questions from the community member. This has a significant impact on the navigation model as well as on how “best practices” are formed by the navigators. Foremost, when navigation is focused on filling out in-take forms while ignoring patients’ questions, comments, and concerns; navigation moves from eliminating barriers to signing up as many people as possible for screenings. This affects the model because patients are left with barriers to healthcare despite being signed up for a cancer screening. This also takes the relationship aspect of navigation out of the model. Relationship building is key to the navigation model because it allows for trust to be built and disclosure to happen.

Despite some navigators only filling out in-take forms others were focused on building rapport with the community members. One such navigator connected with the community by sharing her cancer story, this allowed her to share something personal with her patients which in return granted her a way to build relationships. She commented that patients were more likely to tell her about their concerns and questions after she had told them about her experience with cancer. This can be attributed to disclosure models, where disclosure is more likely to happen once one has already disclosed information (Chaudoir & Fisher, 2010). Other navigators chose to joke with the patients or ask questions about their lives. These provided both the navigator and the patient the opportunity to gain knowledge about the other which ultimately builds trust and provides a chance for disclosure to happen. Although disclosure plays a key role in this aspect of the conversation, listening is also a central component.

Listening is a contextual process by which individuals receive, construct meaning, and respond to spoken and/or nonverbal messages (Arnold, Coran, & Koropeckyj-Cox, 2016).
Listening is regarded as a central component within a healthcare interaction because listening is essential for gathering data, diagnosis, and treatment choice (Jagosh, Boudreau, Steinert, MacDonald & Ingram, 2011). Listening is also a determinant in patient satisfaction (Brown, Butow, Henman, Dunn, Boyle, & Taterstall, 2002; Wanzer, Booth-Butterfield, & Gruber, 2004). Although navigators do not diagnose or treat patients, satisfaction and information gathering is essential to the success of navigation. Here navigators negotiate which type of listening is most applicable to the navigation process. Some navigators chose to utilize therapeutic listening. These navigators associate their role as a mode to demonstrate empathy while filling out intake forms. These navigators listen to the community members, write down what they are saying on the intake form and nod or use phrases like “okay, got it” and “alright”. As mentioned, this type of listening demonstrates and promotes empathy which, is key to patient-centered and culturally competent care (Arnold, Coran, & Koropeckyj-Cox, 2016). These navigators are indicating that the “best practices” of navigation are in the demonstration of understanding and promotion of empathy. However, some navigators appeared to utilize other listening strategies.

The majority of navigators seemed to engage in critical listening or evaluating and responding to a message (Arnold, Coran, & Koropeckyj-Cox, 2016). It was indicative that navigators utilized this type of listening because they listened and then provided an opinion or answer based on what they were told. Critical listening is required when healthcare providers are required to make a decision, form an opinion and/or solve a problem (Wolvin & Coakley, 1996). Often this type of listening was best demonstrated when navigators were confronted with barriers the community member was facing. These conversations were often initiated by the community member saying, “I need to see a doctor but I don’t have time or money to get there.” Navigators would then be required to evaluate and respond with the best course of action, saying “I can help
assist with transportation and insurance, if that would help?” Utilizing critical listening indicates that navigator’s determine and evaluate barriers to obtaining care expressed by the community member and then respond appropriately. This negotiation of the role of navigation reinforces the values and goals of the organization, mainly a navigator is a community member who are available to help at-risk low income patients enter the medical system and eliminate any barriers to care. Navigators also chose to use one other type of listening.

The last type of listening used by the navigators was empathetic listening. Empathic listening requires the listener to understand the feelings and emotions of the speaker and to respond with appropriate attending behaviors and acknowledge the patient’s feelings (Suchman, Markakis, Beckman, & Frankel, 1997). Navigators who chose to use this kind of listening often remarked “Oh, I am so sorry to hear that” or “Congratulation, [on being cancer free] make sure you are keeping up with your doctors appointments.” Navigators who chose to use empathic listening negotiated the role of a navigator further. Not only are these navigators concerned with eliminating barriers to care but are also concerned with the livelihood of the community to which they are serving. Listening offers an opening for interrogating inequalities among the distribution of power, by attending to the unvoiced assumptions and values underlying the concentration of power in the hands of the elite (Dutta, 2014). Therefore, understanding how listening is negotiated by the navigators is significant in understanding how navigators will continue the navigation process and how navigators understand their role as a navigator in the broader scope of cancer care. Listening, however, was not the only aspect to influence this section of the conversation.

At this stage of the conversation, there were issues surrounding whether or not patients have a primary care physician (PCP) or not. The CJN is partnered with Crossroad Health Center,
which is not permitted to take patients whom already have a PCP. This has become an issue with the navigation of patients. Often, navigators ask, “Do you have a doctor?” if the patient says, “yes”, the navigators end the conversation and if the patient says, “no”, navigation is continued. When navigators turn patients who have doctors away, it has serious implications on the navigation process. The picking and choosing reflects the idea that navigators can only navigate you if you are completely disenfranchised. In this scenario, “best practices” are defined as helping the community, if they do not have any resources but if they have resources or have taken steps toward care, navigators cannot help. After the conversation surrounding navigation, navigators are confronted with ending the conversation

**Ending the Conversation**

The observations during the ending conversations were guided by three primary questions, “Did the navigator “navigate” anyone for a screening?”, “If yes, did the navigator explain the next steps?”, and “Did the navigator explain further navigation opportunities” Navigators chose to construct closing conversations in various ways, which influenced how best practices were seen as being negotiated and communicated. The third aspect of negotiation demonstrated by the navigators was in ending conversations. The process of ending conversations centered on one main aspect: continuing navigation or leaving the conversation with no more opportunity for navigation.

Often navigators just ended the conversation. These navigators would say phrases such as, “thank you for your time, have a good evening” or “Okay, thank you”. This affects the “best practices” because it communicates that once the in-take form is filled out or the conversation is over that the navigation process is over. Navigation in this scenario is only applied to initial steps of becoming accustomed to the healthcare system and not to eliminating further and current
barriers. However, some navigators chose to work with the patient while getting them signed up for a screening. This took navigation one step further than those who just ended conversations. With the navigator present during the screening sign up, they are able to answer questions, encourage the patient, and provide additional opportunities to navigation. This communicates that navigation is not just signing patients up for screenings but that navigators are there to eliminate barriers for the patients. Furthermore, some navigators took this further by giving the patient a CJN business card and stating, “Please call me if you have any questions or concerns. I can also help with insurance and transportation.” This is significant in the process of navigation because it demonstrates how the traditional model is transformed into the CJN model. This also communicates to the community that navigation is a multidimensional and cross-contextual process.

**Discussion**

As mentioned, patient navigation is an established process by which trained community members guide at-risk, low income individuals from their community through the complexity of the healthcare system. Previous research has illuminated the significance of patient navigation in improving cancer outcomes in populations who face substantial health disparities (Freeman. 2004). This study took an ethnographic approach to understanding the “best practices” of the patient navigation relationship, through observation of a local non-profit organization (Cancer Justice Network).

Through examination of the texts provided by the CJN, this study established a working definition of a navigator within the CJN model versus the traditional Freeman model. The main point of difference between the two models is that the Freeman model operates with patients who are already established within the medical system; while, the CJN aims to assist individuals into
the medical system that, for a variety of reasons, are not within it. This reinforces the idea that navigation is contextual and adaptable to the characteristics of the organization, community, and the navigators. Moreover, the texts revealed that issues of structure and agency played a significant role in conceptualizing navigation. Structural inequalities were a key point of emphasis for the CJN. The organization described and explained structural barriers (financial, transportation, etc.) that the community potentially faces and how navigation can eliminate these barriers. Additionally, the concept of navigation embodies the foundation of agency as it taps into the potential for individuals to wrest back control of their health from the healthcare system. The patient navigators are facilitators of communication that allow for the voices of the subaltern communities to be heard and recognized.

Participant observation was used to examine the construction and negotiation of “best practices” by navigators during CJN events. This portion of the analysis revealed that navigators define and negotiate their role as a navigator based on interpretation of what their role is. More importantly, this portion of the study manifested ideal communicative strategies in order for the navigator to obtain the best response from the community and co-create spaces for disclosure. When opening a conversation with a community member it is ideal that the navigator introduces themselves, the organization, and their role in addition to some kind of relational phrase (i.e. how are you doing?). Navigators who chose this method of introduction were the most successful in gaining responses from the community. When talking about navigation with a community member, the study yielded that listening played a key part of the conversation. Mainly, empathic and critical listening were the most utilized and useful in the navigation conversation. Finally, when closing the conversation, the study found that it was significant for navigators to explain the next steps for navigation.
Patient navigation is an established process but relies on adaptability, resourcefulness, and relational understanding of the community to be successful. Although the CJN is a new organization, in the beginning stages of navigation, the patient navigators from the organization demonstrated that the roles and responsibilities of navigation are negotiable and communicated differently depending on the navigator.

Understanding, how the navigators constructed, negotiated and challenged their role throughout the course of the conversations with the community plays an important role in disclosure and listening. Receiver assessments, specifically quality, played an important role in the navigator conversations. The literature explains that when assessing the receiver, quality is a determining factor in whether or not an individual will disclose information; individuals often choose to disclose information to others to which they feel “close” and they believe they can trust (Greene et al., 2012; Greene, 2009; Petronio, 2002). This was demonstrated in the navigation conversations. The more relationship building and time the navigators spent getting to know the community the more receptive and likely the community members were to disclose health information. Furthermore, this research illuminated that third party individuals can play an important role in disclosure of health information; specifically if there are strong relationships between the patient and the third party individual. However, additional research is required to understand the impact and extent of a third party role in the disclosure process.

Moreover, this study took an in-depth look at listening in third party health interactions. Previous studies explain that listening is regarded as a central component within a healthcare interaction because listening is essential for gathering data, diagnosis, and treatment choice (Jagosh, Boudreau, Steinert, MacDonald & Ingram, 2011). Upon examining the navigator-community conversations it was apparent that the subtypes of discriminative and comprehensive
listening were present; demonstrating that listening is not only central to the patient-provider relationship but key in other healthcare interactions. Navigator-community conversations are centered on two subtypes of listening: therapeutic and empathetic.

Therapeutic listening, traditionally, uses a supportive rather than defensive communication style, demonstrates attending behaviors (nodding or vocalized representations of understanding), and engages in note taking and/or committing the messages to memory. (Wolvin & Coakley, 1996; Coran, & Hagen, 2012; Delbene, 2015; Arnold, Coran, & Koropeckyj-Cox, 2016). When using therapeutic listening navigators are able to show their support while taking/committing the messages to memory. This is most significant when navigators are learning new information about the patients as well as filling out the in-take forms. Empathetic listening, requires the listener to understand the feelings and emotions of the speaker and to respond with appropriate attending behaviors and acknowledge the patient’s feelings (Suchman, Markakis, Beckman, & Frankel, 1997). When using therapeutic listening navigators are able to understand and respond to the community. This is most significant when considering the information being shared with the navigators and the relationships they have formed. Being an empathetic ear allows for mutual understanding by the navigator and the community. That mutual understanding has the potential to lead to more disclosure and higher navigator successes.

In addition to listening and disclosure, it is important to consider the role of the culture-centered approach within the CJN and patient navigation more generally, specifically partnerships. An argument can be made that the CJN and navigation is not a true CCA partnership and more an elite partnership between organization and community. Within the CCA framework organizations utilize the community members as a central component to operations (i.e. the voices of the community are being utilized and/or community members are key figures
in the organization). Within the CJN, this is not the case. However, a key factor is not considered in this critique—context. The CJN is a new organization who has been building their network and establishing an identity while attempting to utilize the voices and experiences of the community. The CJN operates alongside other community organizations and although the community they serve does not directly influence decision making; they play an indirect role. Community members often tell board members and navigators their thoughts and concerns which are then taken back to meetings and utilized to better the community partnerships. As the organization continues to grow and establish their identity the partnerships will become more apparent and more readily identifiable within a culture-centered framework.
References


Freeman, H. P. (2012). The origin, evolution, and principles of patient navigation. Cancer Epidemiology Biomarkers & Prevention, 21(10), 1614-1617


Pasick, R. J., Barker, J. C., Otero-Sabogal, R., Burke, N., Joseph, G., & Guerra, C. (2009). Intention, subjective norms, and cancer screening in the context of relational culture. Health Education & Behavior, 36(Suppl. 1), 91S-110S.


Appendix A

NAME __________________________________________ # Navigated________

**Opening the Conversation**

Did the navigator introduce themselves?  
Yes _____ No _______

Did the navigator talk about the CJN?  
Yes _____ No _______

Did the navigator explain their role?  
Yes _____ No _______

Comments:

**Navigation Conversation**

Did the navigator answer medical questions?  
Yes _____ No _______

Did the navigator know how to answer questions?  
Yes _____ Somewhat _____ No ______

Did the conversation seem forced by the navigator?  
Yes _____ Somewhat _____ No ______

Did the navigator try to connect with the patients?  
Yes _____ Somewhat _____ No ______

When did the navigator fill out the intake form?  
During _____ After ______

Did the navigator handle lack of knowledge from the patient well?  
Yes _____ No ______

Comments:
Ending the Conversation/ Screening Sign-Ups

Did the navigator “navigate” anyone to sign up for a screening?  Yes _____ No _____
If yes, did the navigator explain the next steps?  Yes _____ No _____
Did the navigator explain further navigation opportunities?  Yes _____ No _____
Comments:

Navigator Presence

Did the navigator stand while speaking?  Yes _____ No _____
Did the navigator sit while speaking?  Yes _____ No _____
Did the navigator make eye-contact?  Yes _____ No _____
How was the navigator’s speaking rate?  Slow _____ Moderate _____ Fast _____
How was the navigator’s tone?  Low/Quiet _____ Moderate _____ Loud _____
Was the navigator conversational or distant?  Conversational _____ Distant _____
Was the navigator enthusiastic in their conversations?  Yes _____ No _____
Was the navigator confident in their conversations?  Yes _____ No _____
Did the navigator use gestures to explain anything?  Yes _____ No _____
Comments:
Post Meeting Observer Reflections

How (if at all) was the CCA reflected at this patient navigation meeting?

How would you describe the “best practices” of a navigator based on observation at this meeting?

How would you say the roles of patient navigation were constructed, negotiated, or challenged?