

THE PREVALENCE OF ADVANCE CARE DIRECTIVES FOR LATINOS WITH CANCER  
IN EASTERN NORTH CAROLINA

by

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## The Prevalence of Advance Care Directives for Latinos with Cancer in Eastern North Carolina

### **Background/ Significance**

According to a study by Huang, Neuhaus, & Chiong, 40.6% of Americans who are over 49 years old will have an advance directive (2016). An advance directive is a document containing a patient's wishes for care during their end of life. These documents are important in protecting the patients autonomy when they are unable to make their own healthcare decisions, as well as providing stress relief for families and surrogate decision-makers.

As of 2016, a white American adult aged 50 years or more was 44% likely to have an advance directive on file, while a Latino American adult of the same age group was only 29% likely to have one (Huang, Neuhaus, & Chiong, 2016). With such a low percentage of Latinos utilizing advance directives, there is a much higher probability that the healthcare wishes of most Latinos are not being honored during their end of life.

Within their lifetime, around 33% of Latino men and women will be diagnosed with a form of cancer (American Cancer Society, 2018). Additionally, cancer has been proven to be the number one cause of death among Latinos (American Cancer Society, 2018). In 2016, 21% of Latino deaths were due to a complication of cancer (American Cancer Society, 2018). These statistics emphasize the need for advance care planning within the Latino community. When a person is diagnosed with cancer, no matter their age or ethnicity, they may face their end of life decisions rather quickly. In order to maintain patient autonomy, it is best practice that all patients diagnosed with cancer be provided with advance care planning (Agarwal & Epstein, 2018). For this reason, physicians caring for these patients must provide adequate advance care planning opportunities. In a 2017 study, it was found that documentation of advance care planning conversations between oncologists and patients was only around 10% (Bestvina & Polite).

There are many possible reasons as to why Latino Americans face such a lower rate of advance directive utilization. Insurance status, home location, and gender are just a few of the factors that may contribute to the limited accessibility of palliative care planning for Latinos (Luque, Soulen, Davila, & Cartmell, 2018). It is important to explore factors that influence the prevalence of advance directives in the Latino community. Once the main driving forces preventing Latinos from utilizing this important part of end of life care is determined, this issue may be alleviated with the proper interventions.

### **Literature Review/ Synthesis**

The disparities faced by Latino patients in palliative care is a topic that has been explored by many researchers in recent years. Nearly three-fourths of Hispanics reported that they had never even heard of palliative care (Huo, Hong, Grewal, Yadav, Heller, Bian, & Wilkie, 2019). This finding was supported in a study conducted by Barwise, Cheville, Wieland, Gaijic, & Greenberg-Worisek, which also found that around 70% of American-born Latinos lacked knowledge of palliative care (2019). One study found that Hispanics are less likely than white individuals to have a living will, a form of advance directive (Orlovic, Smith, & Mossialos, 2019). This may be due to the lack of knowledge available to the Latino community about advance directives (Johnson, 2013).

A possible reason for confusion and lack of knowledge pertaining to end of life and hospice care may be related to historic Latin traditions (Rising, Hassouneh, Lutz, Berry, & Lee, 2019). *Hospicios*, the direct Spanish translation for the English word 'Hospice', were Latin American institutions that were created for the poor (Rising, et al. 2019). This translational incongruence may make conversations about hospice difficult to approach, as many Latinos may become confused that they are being placed into a category of destitution. Education level may

be an important predictor for a person's knowledge on palliative care (Barwise, et al. 2019), possibly because a higher education allows for more open, critical understanding.

Findings from one study suggest lack of access to advance care planning was a major determinant in the likelihood of Latino individuals to have adequate end-of-life plans (Metchnikoff, Naughton, & Peryakoil, 2018). There have also been many preferences noted in Latino patients that may play a role in their willingness to have advance directives. Cervantes, Jones, Linas, & Fischer found that many Latinos have a strong cultural belief of family group decision-making and prefer to have advance care conversations in a home setting with a person who is culturally competent and able to communicate with them effectively (2017). This cultural understanding was noted in a later study which found that acknowledgement of differences between cultures and recruiting providers with an understanding of these values could provide a higher and more congruent level of care for Latino patients (McCleskey & Cain, 2019). In a study done on Guatemalan Latinos, there were three main support systems that were recognized as interdependent factors in relief of suffering. Family was the first of these support systems, with their role being part of decision making and providers of physical care for the patient. The second support system noted was a rezadora, which is a spiritual leader within the Latino community, prays for the patient and prepares an altar in their home. Finally, a priest is the third portion of the support system triad, with their role as a provider for traditional sacraments according to the individuals religious beliefs (Traister, Larson, & Hagwood, 2018). The information presented through this research study, and those discussed previously, provide support to the idea that it is important to recognize the unique palliative care preferences that may be present in the Latino population.

Interventions to help Latino patients through the decision-making process of end of life care have been investigated in multiple recent studies. Fischer, Kline, Min, Okuyama-Sasaki, & Fink looked at the ability of a culturally tailored patient navigator intervention to promote advance directives and hospice use by patient facing end of life care decisions (2018). This study showed that utilizing this intervention increased in the likelihood of patients having an advance directive on file at their end of life (Fischer, et al, 2018). A Latino lay health advisor advance care planning training program was implemented in eastern North Carolina in 2019 (Hagwood & Larson). This training program provided lay health advisors with increased confidence in their abilities talking about advance care planning. They also relayed their understanding that meeting the spiritual and familial needs was just as important as meeting the physical needs of the patients. This study showed that training Latino lay health advisors has great potential to lessen disparities in palliative healthcare delivery faced by Latino with serious illnesses (Hagwood & Larson, 2019).

### **Research Questions/Aims**

This research project will explore the utilization of advance directives among Latinos in eastern North Carolina (ENC). Specifically, we will examine Latinos diagnosed with cancer within the Vidant Healthcare system. The analysis will look to answer two research questions.

#### Do Latinos with cancer in ENC have documentation of Advance Directives?

First, we will examine whether or not Latinos with cancer have a documented advance directive in the hospital's electronic healthcare record (EHR). This will be key in understanding the prevalence of advanced directives among Latinos with cancer in ENC. Through answering this question, a comparison can be drawn between the percentages of Latinos with documented advance directives on a national level, mentioned previously, and those in ENC.

Additionally, this data will allow us to potentially compare the rates of advance directive use between races and ethnicities in eastern North Carolina, to see if they are parallel with the findings of Huang, Neuhaus, & Chiong (2016).

### Among Latinos with a documented advance directive, what choices did they make about EOL care?

It is important to look at the choices the patients made in their end of life care planning. There are many elements of a person's life that play a role in their decision making. For example, religious beliefs or familial considerations might influence a person to choose less medical intervention towards end of life (LoPresti, Dement, & Gold, 2016). Additionally, a patient's choices might be swayed based on misinformation or a negative stigma surrounding their disease process (Rising, Hassouneh, Lutz, Berry, & Lee, 2019).

## **Methodology**

### Study Design

This study was a retrospective chart review.

### Assessment/ Data Collection

Data was collected through a retrospective chart review of Latino patients diagnosed with cancer in the Vidant Medical system in the year of 2018. All data, including demographics, were extracted from electronic medical records and managed using REDCap electronic data capture tools hosted at East Carolina University. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and

interoperability with external sources (Harris, Taylor, Thielke, Payne, Gonzalez, & Conde, 2009; Harris, Taylor, Minor, Elliott, Fernandez, O'Neal, McLeod, Delacqua, Kirby, & Duda, 2019).

First, we identified whether or not there was an advance directive on file in the EHR. Advance directives were defined as a healthcare power of attorney or a living will. Among individuals with a documented living will, the specific choices made on the document were recorded. Additionally, patient's age, gender, marital status, and insurance status were extracted. The zip codes of patients were used to code participants as urban or rural residents.

### Sample/ Setting

This study explored Latinos who were diagnosed with cancer within the Vidant Healthcare System between January 1, 2018 and December 31, 2018. The patients were only considered if they were diagnosed and cared for on an inpatient basis during the year of 2018.

### Analysis

The sample, demographics, and main findings were analyzed using descriptive statistics.

### **Results**

A total of 41 records were included in the data analysis. In this sample, 100% of the participants were of Latino ethnicity. Of the patients included, the mean age was 49.1 years (SD = 17.5, range = 20 to 87). The majority of patients were male (56.1%, n = 23) and were single (48.8%, n = 20). Nearly half of participants did not have insurance (43.9%, n = 18). Of those who were insured, the most prevalent type of insurance coverage was Medicaid (26.8%, n = 11). The majority of patients lived in a rural county (53.7%, n = 22). Demographic characteristics are outlined in Table 1.

**Table 1.** Demographic Characteristics of Participants

Characteristics	<u>Mean</u>	<u>SD</u>
Age	49.1	17.5
	<u>n (%)</u>	
Gender		
Male	23 (56.1)	
Female	18 (43.9)	
Insurance Type		
None	18 (43.9)	
Medicaid	11 (26.8)	
Medicare	7 (17.1)	
Marital Status		
Single	20 (48.8)	
Single living with partner	1 (2.4)	
Married	17 (41.5)	
Widowed	3 (7.3)	
Residence		
Rural	22 (53.7)	
Urban	19 (46.3)	

All participants were diagnosed with some type of cancer but specific types of cancer and stage of disease were not collected or analyzed in this study. At the time of data collection, 26.8% (n = 11) were deceased. There were 22% (n = 9) of individuals who had a ‘Do Not Resuscitate’ order on file. While only 17.1% (n = 7) of those in the sample received a palliative care consult, there were no individuals who received an advance directive consultation while receiving care on an inpatient unit. Only one individual was sent to home hospice and no individuals were discharged to a palliative care unit. 97.6% (n = 40). These characteristics are outlined in Table 2.



<b>Table 2. Clinical Characteristics of Sample</b>		
Characteristics	Yes n (%)	No n (%)
Deceased	11 (26.8)	30 (73.2)
Advance Directive Consult	0 (0)	41 (100)
Completed Advance Directive	1 (2.4)	40 (97.6)
Palliative Care Consult	7 (17.1)	34 (82.9)
Palliative Care Unit Use	0 (0)	41 (100)
Hospice Use	1 (2.4)	40 (97.6)

## **Discussion**

All patients diagnosed with cancer should receive adequate end-of-life care planning consultations (Agarwal & Epstein, 2018), which should include information about and completion of advance care planning documents. This study aimed to explore the prevalence of completed advance care planning documents among Latinos with cancer who received inpatient care in Eastern North Carolina. Additionally, we sought to examine the types of choices Latinos with cancer made in living wills, but the completion rate of living wills was so low we were not able to complete this analysis.

Research shows the benefits and importance of advance directives during end-of-life (Agarwal & Epstein, 2018), yet less than half of Americans over 49 years old will have an advance directive on file (Huang, Neuhaus, & Chiong, 2016). With cancer being the number one cause of death within the Latino community, proper advance care planning holds a strong importance (American Cancer Society, 2018). However, in a previous study, Latinos were shown to complete fewer advance directives and healthcare power of attorney documents in comparison to other ethnic groups (Huang, Neuhaus, & Chiong, 2016). In our study, only one participant had documentation of a living will in the EHR. We found almost no advance directives documented in the EHR for the 41 Latinos with cancer in Eastern North Carolina (96.7%, n = 40). These

findings are congruent with those of past research studies. One of the major differences between our study and other studies is that we did not include a comparison group. Nonetheless, rates of completed advance directive documents in our study are unacceptable.

Luque, et al. found that insurance status, region, and gender may contribute to the lack of advance care planning utilization within the Latino community (2018). In our study, 43.9% (n = 18) of patients were uninsured and 26.8% (n = 11) of patients were insured under Medicaid. Additionally, participants in our study live in a primarily rural region of the country. Thus, these factors may have contributed to rates of advance directive completion.

Previous research has shown that a majority of Hispanics lack knowledge about palliative care resources (Barwise, et al., 2019; Huo, et al., 2019), which can include making decisions about advance care planning. The lack of completed advance directives in the Latino community may be directly related to their deficiency in knowledge on the subject (Johnson, 2013). Our study supports this previous finding. In our sample, only 17.1% (n = 7) of individuals received a palliative care consultation and no individuals in received an advance directive consultation.

In our sample, there were 11 individuals (26.8%) with a documented date of death in their record. Our results show that only 17.1% (n = 7) of total participants received a palliative care consult, 2.4% (n = 1) were discharged to hospice, and 2.4% (n = 1) had an advance directive on file. This data indicates individuals in our sample may not have had clear plans for their end of life care, thus their wishes for end of life care may not have been followed. Additionally, the lack of hospice use in our sample, as well as the number of palliative care consultations, is concerning. Though determining causality is outside the scope of this study, this data indicate Latinos with cancer in ENC may experience disparities in end of life care.

## **Implications for Practice**

The diagnosis of cancer can have many consequences for patients, including death. For this reason, all patients diagnosed with any type of cancer should complete advance care planning documents. One way to improve completion rates of these documents are advance directive and palliative care consults for those who are admitted for inpatient care. These consults can provide the information and resources individuals need to make educated end-of-life planning decisions. These decisions include, but are not limited to, completion of an Advance Directive, establishment of a Healthcare Power of Attorney, or DNR status changes. In order to ensure that these resources and consults are being provided to patients diagnosed with cancer, an interprofessional palliative care team could be established in appropriate facilities so that they may be available to use a patient-centered care model to reach all patients faced with this diagnosis.

## **Limitations to the Study**

There are several limitations to this study. This was a retrospective chart review. All of the data collected was only what was able to be located within the Electronic Health Record. Data was only available while the individuals was on an inpatient unit and ceased once someone was discharged from the hospital. Additionally, due to the inclusion and exclusion criteria, only a small sample (N = 41) of patients were able to be examined. This makes the findings hard to generalize to other patient populations and to other geographic regions. There is no comparison group examined in this study, making it hard to determine if this is an ethnic disparity, or a regional one. Finally, we did not collection information about type of cancer or stage of disease. Individuals with early stage cancer may be less likely complete advance care planning documents.

## **Recommendations for Future Research**

It was beyond the scope of this study to determine if the Latino ethnicity or other sociodemographic factors played a role in the lack of palliative and end-of-life care planning. Future studies should examine a larger sample of Latino individuals with cancer and include individuals with both early and late stage disease. Additionally, future studies should include hospitals from a larger geographic area. There should also be further exploration into the hospital palliative care system to explore what available resources are available and culturally appropriate for Latinos with cancer. Future qualitative studies should examine obstacles these programs face when implementing culturally appropriate advance care planning consultations.

## **Conclusions**

This study explored the utilization of advance care planning among Latinos with cancer who were admitted to an inpatient hospital unit in Eastern North Carolina. Most individuals were single males with either no insurance or Medicaid. Most individuals in our study did not have any advance care planning consults. Nearly all participants did not have advance care planning documents in the EHR. Because of the limitations of this study, it cannot be concluded what sociodemographic characteristics are contributing factors to the lack of advance care planning utilization. However, further research can explore these demographics to further identify factors related to the unacceptable numbers related to advance directives, DNR status, healthcare power of attorneys, and hospice admissions. This study demonstrates an extreme need for palliative care education and expansion of end-of-life resources for Latinos with cancer in Eastern North Carolina.

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