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Abstract

Central Coast Visiting Nurses Association is a non-profit agency that provides home health care as well as hospice care for individuals in the counties of Monterey, San Benito, Santa Cruz and Santa Clara. In this region, the Latino/ Hispanic communities are underutilizing the services for end of life care. According to statistics provided by VNA 2019, only around 20% of the populations they serve are Latino/ Hispanics. Education on end of life care services is necessary for an individual to have a better understanding and quality of life during the end stage or confronted with a life limiting illness. In Monterey county, according to US Census Bureau 2010, 55% of the population is of Latino/Hispanic ethnicity, and VNA does not have many employees who are Spanish speaking, therefore are unable to present information about end of life care services to Latinos/Hispanics in Spanish, thus creating a problem for the agency. This project was aimed to create awareness in the Latino/Hispanic communities about end of life care services offered through VNA via a Spanish educational presentation on October 7, 2019 held at the Camphora Community Center in South Monterey County. The outcome of creating awareness on end of life care services in a Spanish speaking Latino/ Hispanic community was achieved. All of the participants who attended the Spanish educational presentation identified via a survey they would be interested in or maybe interested in receiving services from VNA, if they were in need of support during end of life. The results of the presentation provided evidence that if VNA creates educational presentations in the language most frequently spoken in a community, in this case Spanish, it overcomes some barriers the agency faces. The services would be accepted by more communities regardless if is a difficult subject to touch, such as end

of life care. Future recommendations include more Spanish educational presentations for Latino/Hispanic spanish speaking communities in different areas of the regions they serve.

Keywords: hospice, end of life, awareness, educational presentation

Agency & Communities Served

Central Coast VNA agency was established in 1951 providing home health care as well as hospice care. According to the American Cancer Society (2019), “hospice care is a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life limiting illness”. The mission statement at VNA states, “ VNA is dedicated to providing the highest quality health care to residents of the Central Coast by meeting their individual needs in a caring, effective, honorable, and accessible manner” (2019). This agency is a non profit and funded through private insurance, medicare, donors, grants, Medicaid, veteran’s benefits, and even out of pocket costs. It specifically includes three different services which are hospice, home health care and wellness and immunization services. The populations that it mainly serves are individuals in the age range of 85 years and older and with 73.3% of the population being caucasian race(VNA admissions, 2018).

There are many collaborating partners associated with VNA, many of whom are sponsors and financial contributors. One of the collaborative partners is Salinas Valley Memorial Hospital. Salinas Valley Memorial Hospital sends referrals to VNA in order for patients to receive care for their illness or end of life care at home. Also, SVMH provides space for VNA immunization clinic events to occur.

One of the programs at VNA is the hospice program, which aids those individuals who are at their end of life stage. This program addresses the physical, emotional, social and spiritual needs at their end of life stage not only for the client but their families too. This program is offered in many different settings. It is available to the client at their home, skilled nursing facility, residential care facilities or where the patient calls home. Hospice provides an

opportunity for a patient to have a better quality of life during a life limiting illness and a patient to depart this life with dignity.

Problem Description

End of life care as defined by the US Department of Health and Human Services (2019) as, “the support and medical care given during the time surrounding death”. “ Around 600,000 Americans died from cancer in 2016. This is nearly 185 deaths for every 100,000 people in the United States” (Livestories, 2019). Heart Disease is the leading cause of death in the U.S. causing about 1 in every 4 deaths. With cancer and heart disease as the leading causes of death in the United States there is a great need for end of life care in all areas of the country. Latinos comprise 15% of the total US population (Kreling, 2002). Locally, in Monterey County, 55% of the population is of Hispanic and Latino ethnicity (US Census, 2010), therefore, it is essential to educate because end of life care at hospice level is still underutilized by the Latino community. According to the VNA admissions department, in 2018 Latinos/ Hispanics made up only 20% of the populations they serve.

Contributing Factors

One issue that affects residents all over the United States, is the need for affordable healthcare insurance and its impact on obtaining end of life care services. An example of local statistics include the population of Monterey County. Out of the estimated population of 437,907 individuals in Monterey County, 11% are individuals under 65 years of age without health insurance (U.S. Census, 2010). With no health insurance the cost of end of life services are very expensive ,therefore many individuals decide not to take approaches to end of life care. Outpatient hospice services cost an average 15 times less than treating the dying in a hospital. It

is between \$100 to \$200 an outpatient per day while in the hospital it can be close to \$3,000 per day (Betancourt, 2016). Insurances can also have strict regulations on what medications or treatments they will cover or what diagnosis are needed to qualify for palliative or hospice services. Medicare pays for nearly half of home health and hospice care (Deloitte 2019). Therefore, the individuals who do not have Medicare might have a harder time accessing end of life services. “Given that the vast majority of people who die are elderly, Medicare is the primarily health insurer for more than 80% of the people who die each year in the United States” (Wiener , Tilly, 2003). There are still those 28 million people in the United States who do not have health insurance and for the dying and their families lack of insurance is devastating (Betancourt, 2016).

Another important cause is the lack of awareness and education on end of life care services. Many individuals are not aware that such services exist. There are cultural boundaries that might prevent their knowledge to expand. “ Latino families frequently do not want to discuss the actual death, control is usually kept within the family and the patient is often “protected” from information and the responsibility of making decisions” (Kreling, 2002). For example, in the Latino community it is not common that someone outside the family cares for the ill only the immediate family should. Not being informed on the services that may be fundamental in those last days can be a hardship. Many families consider hospice a taboo because they feel their loved ones will be expiring very soon when in reality, they should be provided with the best care possible (Kreling, 2002).

The language is another barrier for the education to be provided. Physicians and staff might not be competent in another language other than English. According to Livestories

statistics, there are 190,233 individuals in Monterey county who are Spanish speaking only, who range between the ages of five to greater than 65 years old (2019). “Hispanics continue to be the fastest growing ethnic group in the U.S. population with a 43% increase between the years 2000 and 2010. As this population continues to grow in number and ethnic diversity, so does the concern about the disparities in how care is provided” (Carrion,Bullock, 2012).

Consequences

One of the consequences that arise with this problem is the low quality of life during end of life stage. U.S. ranks 13th in the quality of life index among 77 different countries in the world (Numbeo, 2019). “Beyond the essential ideas of broad access to food and housing, to quality education and health care, to employment that will sustain us, quality of life may also include intangibles such as job security, political stability, individual freedom and environmental quality” (U.S. News, 2019). It could be connected to the lack of knowledge of services that can be both beneficial for the family, as well as, for the client.

Each individual has an idea of their death and what actions they need to take when faced with a limited illness. By not providing end of life care, individuals cannot express how they would like to be treated, so they cannot get their death wishes granted. Not having the power to learn about advance directives or to complete their end of life wishes is devastating because they do not get a say in how they would want to die. “ Most people say they would prefer to die at home, yet only about one-third of adults have an advance directive expressing their wishes for end of life care” (CDC, 2019,Pew 2006, AARP 2008). “Among those 60 and older, that number rises to about half of older adults completing a directive. Only 28 percent of home health care patients, 65 percent of nursing home residents and 88 percent of hospice care patients have an

advance directive on record”(CDC 2019, Jones 2011). Not being educated about advance directives can in return not meet death wishes. The following model labeled **Image 1** shows the problem, consequences, and contributing factors.

Capstone Project

Everyone deserves to die with dignity and no one deserves to stand alone during their end of life. Educating the less fortunate or a population with many barriers to receive end of life care is the main focus of this project. I created a presentation for the Spanish speaking Latino population. A presentation in Spanish for the Latino community provides education on what end of life care is, and the services there are for the individuals facing a life limiting illness, as well as, their families and loved ones.

Image 1: Problem Model

Contributing Factors	Problem	Consequences
Lack of insurance	Lack of end of life care in the Latino community	Poor quality of life
Lack of awareness		Death wishes not met
Language Barriers		

Capstone Project Description and Justification

Project Implementation

Implementation of this capstone project included setting up a meeting place for the presentation to occur and develop a presentation along with my mentor. This educational presentation provided necessary information for the Latino Spanish speaking community regarding end of life care services. To set up a meeting area for the presentation to occur many

places had to be taken into consideration depending on the area and capacity of creating that soothing environment for the population. End of life care is not an easy subject to discuss with the Latino population. Therefore, developing a presentation to establish a sense of connection to the culture was most beneficial. First, we had to know what issues and topics we would want to talk about specifically. The VNA services were mentioned in order to connect the community with the agency that can provide the necessary services. The presentation was transcribed through a powerpoint that my mentor approved of. **Appendix Figure 1** summarizes the following: The objective of the project, the project activities, deliverables, and timelines/deadlines for the project implementation.

Project Purpose

Project Title: Planning Ahead: Educating Latinos on End of Life Care Services

This capstone project provided education about end of life care services to the Spanish speaking population in South Monterey County. Enhancing the knowledge of the Latino Spanish speaking community in South Monterey County about end of life care has benefits for patients, caregivers, family members and overall the whole community.

The purpose of this project is to give the Latino community knowledge that there are resources to use from agencies such as VNA. In South Monterey County, there are a lot of Spanish speaking communities that are not aware of what end of life care is or how it can be beneficial for a better quality of life. VNA services can relieve some of the burden from the stress families may feel when dealing with difficult situations, such as having a family member or friend with a life limiting illness. Creating a Spanish presentation about the services during these hard times will in hopes to provide a better understanding of end of life care to a

community that lacks the knowledge and awareness. Everyone should have the opportunity for a better quality of life, and language shouldn't be a barrier.

Project Justification

According to the American Hospice Foundation (2010), “understanding these pertinent cultural differences may help hospice providers reach out to Latinos and improve care for Latino families”. The American Hospice Foundation believes cultural differences should be acknowledged in order to create an improvement. By providing services in Spanish, end of life care can be best acquired in the Latino community. If agencies such as VNA have workshops or presentations in Spanish then families will feel more connected. “The cultural sensitivity and diplomacy required for these tasks suggests the need for trained bilingual, bi-cultural community members who are aware of the values of secrecy and denial, as well as the important role of the family in these decisions” (American Hospice Foundation, 2010). An individual such as myself, who is bilingual can contribute to the engagement of the Spanish speaking community through an educational presentation.

Expected Outcomes

The expected outcome of this educational presentation in Spanish was to increase Latino members knowledge on end of life care and services they can receive through an agency like VNA. Also, to help this population understand the importance of the services that can be provided for someone they care about to have a better quality of life. Also, to decrease the stigma that revolves around hospice care within the Latino community, and educate on the benefits patients have under hospice care.

Assessment Plan

To assess if the expected outcome was reached a post survey was given in Spanish orally to the attendees . Found in the **Appendix Figure 3** is the survey. They were provided with questions in regards to the presentation being beneficial to gain more knowledge on end of life care services, or if after the presentation they would reach out for services with the agency. From there, I evaluated the outcomes and gained data on whether or not the Spanish presentation was functional in gaining knowledge on end of life care services and its benefits.

Project Activities

Arranging the place and contacting the correct personeel for my presentation was a bit confusing at the beginning. My mentor, as the Latino outreach coordinator for VNA, has more connections in the communities, therefore, it was just a matter of speaking with the resident service coordinators of different locations to confirm the date and time of the presentation, and if the meeting room was available. A flyer was produced in order to advertise this presentation, and it was delivered to the community members of Camphora, an area next to the town of Soledad in Southern Monterey County, where the presentation was held. An image of the flyer can be viewed in the **Appendix Figure 2**. Many of the residents in Camphora did not open their doors to explain to them about the information that would be given, so the flyer was left in the door. The flyer was produced in the VNA marketing department who is in charge of arranging all the information of flyers in the correct areas of the paper and print it out. After the flyer was produced, the survey was created.

The presentation had information on the different services VNA has for the community. Information on hospice and palliative care and what the definition of each was presented. Other

information delivered in the Spanish presentation was about how individuals can pay for the VNA services and who to contact. My mentor, as a representative of VNA agency, gave them goodie bags with flyers, water bottles, pens and notepads. There were questions mostly about advance directives and how to complete it, and how advance directives are useful to have.

Project Outcome

The project outcome was to create awareness and give information to the Spanish speaking Latino community members on end of life care services available through VNA in their language. Planning ahead is very important in order to keep a good quality of life during end of life stage or through a life limiting illness. Through a presentation in Spanish, the Latino/Hispanic population will gain a better understanding of what resources can be provided to anyone in the community regardless of their situation. This educational presentation was given in hopes that everyone will have a good quality of life at every stage in their life, and especially during end of life. Also, to make the Latino/Hispanic population aware that they deserve to have their wishes met, and they can start planning ahead for it. VNA is an agency that is very supportive, helpful and dedicated during hard times for a family, therefore, with the knowledge about what VNA offers attendees will in hopes to be more willing to reach out for services.

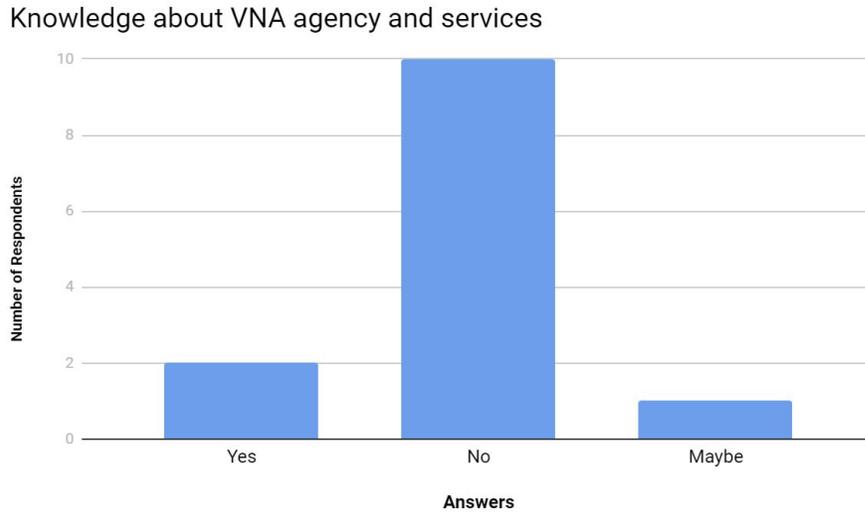
Findings/Results

The presentation was held in the Camphora Center with a total of thirteen attendees who defined themselves as Spanish speaking Latino/Hispanic members. These individuals were not quite sure of what the presentation was about or what it would introduce them to. As expected, the population does not have much knowledge on the topic of end of life care.

This presentation started with introductions and moved forward with an activity. This activity provided them with time to express their wishes as if they were at the end of life stage or faced with a life limiting illness, and what wishes were most important for them. It made individuals realize there are different wishes for each person. What might be important to one person might not have the same importance to another. Having that awareness of what death wishes or life wishes everyone desires to have is not common to express within the Latino/Hispanic community, and they achieved it well without hesitation during the activity.

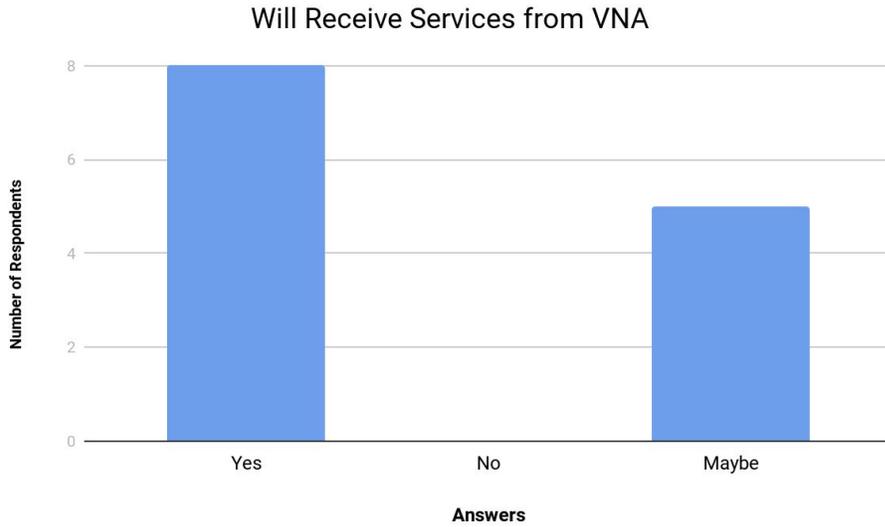
After the presentation, there were questions from the audience mostly regarding advance directives and how to complete them in order to have life wishes granted. Also, all the attendees were asked to fill out a survey. One of the questions that the survey had was about the knowledge of VNA. If they had previous knowledge about VNA agency. The chart shown on **Image 2** below shows the responses given by the 13 attendees. More than 50% of the attendees did not know about VNA, and the services they provided. The lack of awareness was noted within this community.

Image 2: Chart 1



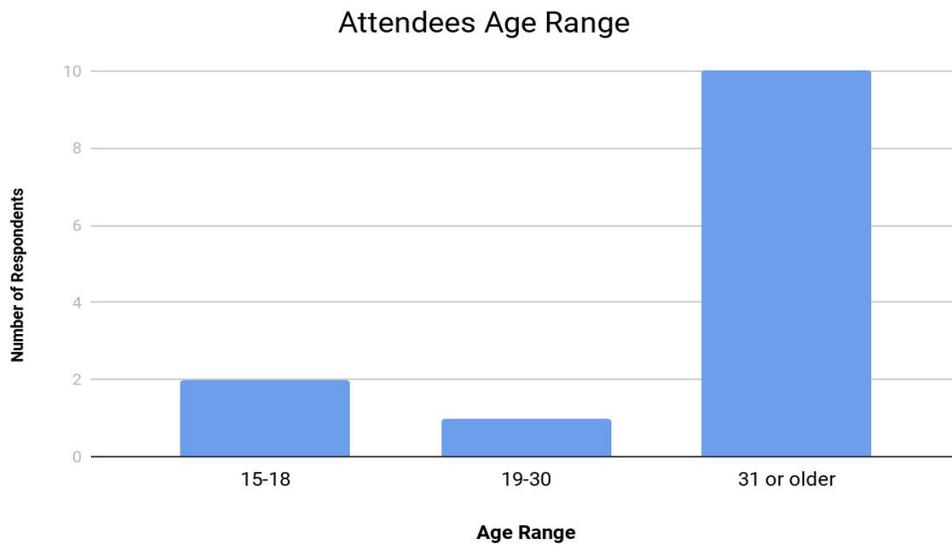
Another question presented in the survey was if VNA would be an agency they would refer to others if they were in the need for such services, of course after listening to the presentation. The impact they had with the presentation served enough for all 13 attendees to mark yes they would refer others to VNA to obtain services. Better yet, a question in the survey asked if they would receive services from VNA if they were at their end of life stage or faced with a life limiting illness, more than 50% answered yes. The chart with the results to the question is shown in **Image 3** below.

Image 3: Chart 2



The majority of the attendees were in the age range of 30 through 50. After analyzing the data, it was found that the average age was 35. The chart below **Image 4** provides an idea of the age ranges of the attendees.

Image 4: Chart 3



Usually the age range above 30 can be considered to have individuals who might have the elderly parents, grandparents or work in areas they might know more families who may benefit from the services of VNA agency, therefore they have more interest in the VNA services, and have marked yes to the survey answers stated above. The good thing in regards to all individuals whom attended the presentation is that no respondent refused to receive VNA assistance. This can determine that the Spanish speaking Latino/ Hispanic population is interested in end of life care services ,as long as they have the knowledge of what it consists of and is explained to them in a language they understand.

With this determinant it concludes the presentation was successful. The Spanish presentation on end of life care services might not have changed the minds of everyone and their beliefs, but it seems to have planted a seed into curiosity. The main goal was to present the information to the Latino Spanish speaking community and create awareness about end of life care services offered through an agency such as VNA. Latinos who participated seemed open about the subject and are willing to refer information about VNA services to others. Marketing the information by word of mouth will hopefully increase the Latino/Hispanic percentage who receive end of life care services.

Conclusion & Recommendations

This project helped me gain the information necessary to conclude that Latino / Hispanic populations are in the need to receive end of life care services. They need more information to be presented in their language, as well as, providers to be able to communicate their services in the clients native language. For example, nurses and therapists should be able to provide the necessary information for medication or treatments rendered to the client in the language they

speak. It is hard enough for a Latino family to be able to open up to receiving services, so the agency should be able to provide the best support to them making them feel supported with staff than can communicate and connect well with them.

A recommendation that would be beneficial for VNA agency is to create workshops to provide training to the staff to gain knowledge on different languages. Also, providing non Spanish speaking employees with Spanish speaking interpreters to go along to visits and provide the support for the Latino families. My mentor has recently taken a new position which began presenting more information to the Latino communities in Southern Monterey County by presentations, resource fairs and workshops, yet the marketing for these events still needs work. By marketing more on social media, city departments of great Latino attendance, such as libraries, city hall meetings, churches would be very beneficial in order for the community to be aware of events.

Personal Reflection

As a daughter of Latino/ Hispanic parents, I feel the obligation of providing the care for my parents during their end of life stage. No one is really prepared to face death, yet it is inevitable. Before working with VNA, I didn't realize the importance of planning ahead and having the knowledge of how we can have our death wishes granted. After my experience working with social workers, I found out the importance of advance directives and completing one. They state your wishes exactly as you want them and no one can go against them once it is filled out. This became something very important for me to implement with my own family.

There had recently been a situation where one of my family members had been under hospice care during her last days. I didn't really understand what benefits hospice provided.

After visiting different hospice patients at their homes, I soon realized they were living their life in comfort with no pain and at peace. They felt happiness and these services were available for them and even companionship was provided, so they would never experience loneliness.

Understanding what end of life care is and what services are around our Monterey County has been an amazing experience. Watching my parents complete their advance directives and knowing that I have provided them with information that might be very beneficial in a future is very rewarding to me. I feel that this capstone experience not only increased the knowledge of Latino / Hispanic individuals, but also made me realize that we should be able to plan ahead with our own family. The quality of life does not begin during our end of life, yet every step we take should be lived with dignity and respect.

For future students, I would recommend a project with the South Monterey County populations. It seems to be an area where a lot of information about resources is needed. Not only for the Latino families but everyone in general. The population has to travel great distances and sometimes it becomes difficult to obtain much information. Some projects that would benefit would be to implement support groups for the families involved in the care of the clients. Providing them with self care tips during hard moments is beneficial for the caregivers.

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Appendix A

Figure 1: Scope of Work

Primary Objective of the project: Increase Latino population knowledge on end of life care		
Activities	Deliverables	Timeline/ Deadline
1. Gain knowledge of the Latino population in South Monterey County	1. Population has a high percentage of Spanish speaking Latinos and other indigineous dialects	July 1, 2019
2. Meet with agencies that can provide a space for a workshop	2. Met with different agencies involved with South Monterey County	August 15, 2019
3. Found an area for the workshop to take place	3. Made sure to get any permits in order with agency	September 1, 2019
4. Develop information for presentation & flyers	4. Meet with mentor to create slides	September 15, 2019
5. Develop Post survey and review with mentor	5. Develop and approve surveys	September 30,2019
6. Promote and hand out flyers or information on workshop	6. Go to different areas in South Monterey County to deliver flyers	October 1-5 2019
7. Implement Educational Presentation	7. Feedback from surveys	October 7,2019
8. Analyze Data	8. Create charts,graphs	October 10,2019

Figure 2: Flyer

VNA

PLANIFICANDO CON ANTICIPACIÓN LA ETAPA FINAL USANDO LA AYUDA DE VNA

Acompañemos a conocer sobre los programas y servicios diseñados para nuestros seres queridos en la etapa final de su vida y como darles el cuidado que se merecen.

Únase a nosotros

Lunes, 7 de octubre
6:00 – 7:00 pm

Camphora Center
2101 McCoy Rd.
Soledad CA, 93960

Por favor contactar a
Elizabeth Brucato 833-241-3838 o
Ana Mediana 833-444-5690
para reservar su espacio.

CCVNA.com

Figure 3: Survey

