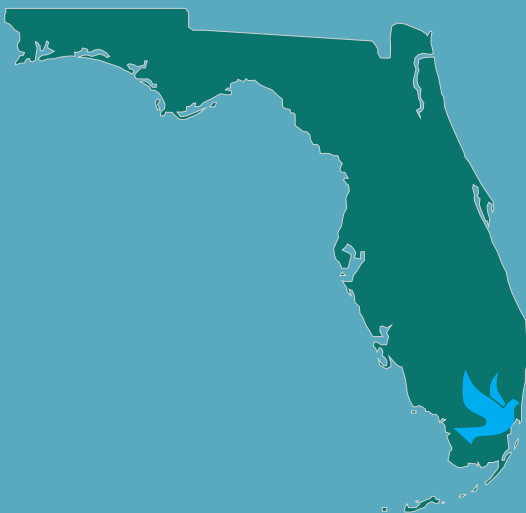




FLORIDA HOSPICE
& PALLIATIVE CARE ASSOCIATION

Understanding the
Hispanic Community's
Hesitancy with End-of-Life Care



Description of Project:

The purpose of this project was to identify cultural barriers in the Hispanic community that steer them away from using Hospice in general. Thanks to the help of the grant, we were able to do a small research project and consider the various factors that may lead to the hesitancy and general underutilization of hospice care by Hispanics in our community. We have based our research on evaluating the several elements that may influence the Hispanic cultures' decisions. See more in Appendix A.

Activities Completed:

Due to budget constraints, we chose to conduct our research through simplified means including using surveys and focus groups. 954 surveys were completed and 2 focus groups were conducted. We were able to gather qualitative information from this investigation. Activities are explained with more detail in Appendix B.

Challenges Encountered:

Our consistent obstacle was the fact that this demographic has difficulty discussing the "end-of-life". Furthermore, a portion of our target demographic (65+) has difficulty writing out and/or understanding open-ended questions due to a language barrier or an age barrier. We had to adjust the wording and ensure employees who were facilitating the surveys were bilingual and capable of working with the demographic. There were other roadblocks that are explained in Appendix C.

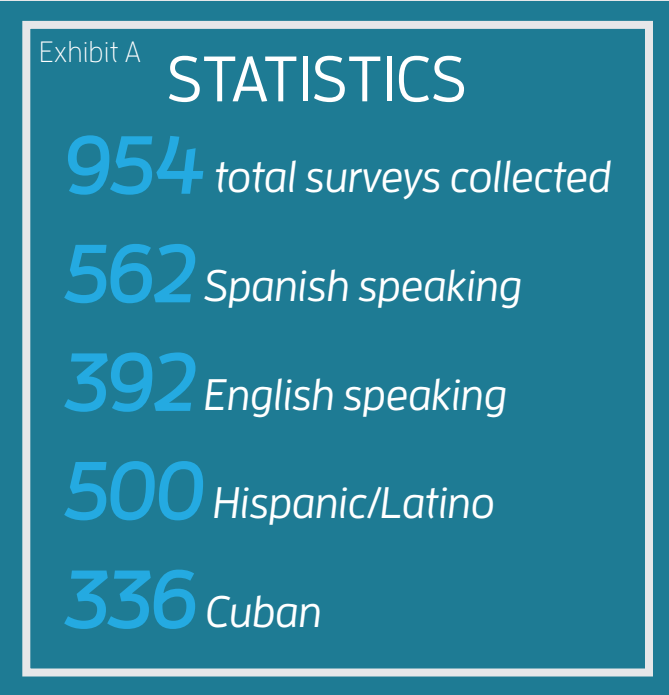
Activities Planned:

We hope to use this information to elevate our message in our Marketing, collateral, educational seminars and especially in training our staff.

While we have understood the general apprehension our demographic has, we now have qualitative information to support it. We now know we should focus on education in our plans.

Money Spent:

We have spent dollars on hours dedicated to this project. Tasks that needed to be performed were development and planning of surveys and focus groups, fulfillment of research plans, analyzing results and compiling the data. See more at Appendix D.



Appendix A

While establishing our strategy for the study, we met with the directors of our interdisciplinary teams to discuss and understand OpusCare’s challenges in reference to the Hispanic community we service.



Physicians



Nurses



**Certified Nursing Assistants
and Home Health Aides**



Social Workers



Chaplains and Spiritual Counselors



Bereavement Coordinators

Through this research grant, we were able to delve deeper into our Miami-Dade community to further see that our main challenges with this ethnicity are, in fact, early identification and education.

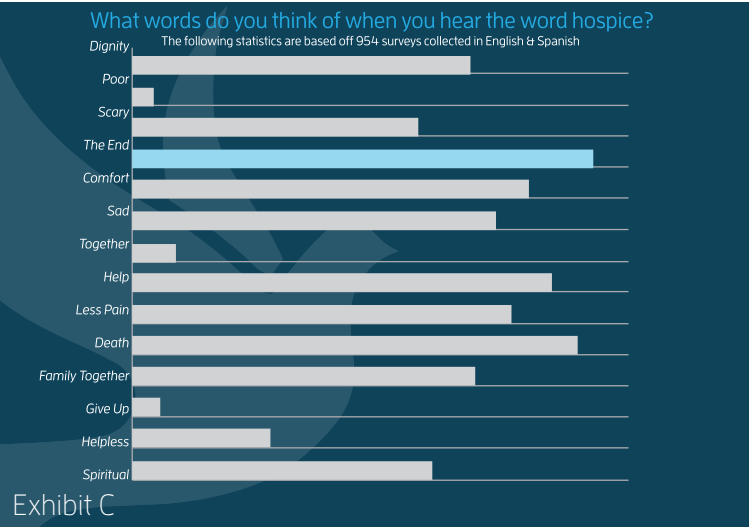
Individuals of the Hispanic community rely on their traditions, beliefs, and religion to make daily decisions. When it comes to bigger decisions, such as when a family member is terminally ill, Hispanics connect even more strongly with their culture, which primarily revolves around family, prayer and their religious communities.

While establishing our strategy for the study, we met with the directors of our interdisciplinary teams to discuss and understand OpusCare’s challenges in reference to the Hispanic community we service. Our main concerns were impediments in communicating services to patients and/or their caregivers. These meetings were pivotal in finding a focus for our exploration of the subject, formatting our survey questions and determining the type of data our team felt important to collect and analyze.

Once we analyzed the results of the survey, we realized that most individuals were associating hospice with “the end” and “death”, as illustrated on the chart in Exhibit C. Most individuals considered hospice the “last resort”, the last possible thing that could be done, because nothing else could be done. This explains the hesitancy and postponement of agreeing to sign a family member onto hospice until the last possible minute, sometimes leaving the patient with only a few days to live instead of having lived their last few months with more comfort and with dignity.

In the Hispanic culture, there is accountability on (adult) children of an individual to take full care of their parents when they fall ill. This expectation leads to hesitancy to have aids in the home of the individual, to rely on outside sources, such as nursing homes, and also leads to a lot of confusion as to what the patient’s last rights are by the time the patient qualifies for Hospice. Many individuals in this culture have not made clear to their family what their last wishes are, leading to confusion, deferment of signing on to hospice and emotional crisis’ during this difficult time.

Furthermore, South Florida is heavily populated with Hispanics from all over South America. The majority is Cuban, but other nationalities include Venezuelan, Colombian, and others. While some of these Hispanic cultures are very traditional, some are more progressive. They are dissimilar enough that research to show the differences and similarities of each and how the hospice industry should treat each is imperative. From our research, it is still unclear if there are unique reasons that there is such a sparse use of hospice care in each culture.



Appendix B

We developed a survey with questions we felt would best capture the sentiment that the individual had toward Hospice care. We narrowed down our questions in order to simplify the survey. We did not want to lose the interest or general attention of the person being surveyed. We chose questions we felt would give us some more detailed information, in order to grasp a more tangible sense of where the hesitancy stemmed from. We had the survey translated to Spanish. See Image Exhibit A to reference statistical data on the surveys we collected.

We distributed the survey both electronically and physically. We used our social media marketing and online presence to not only boost survey fulfillment but also to educate the community on our study. Our primary goal was to gain information and statistics on the subject matter by having the community answer our questions; our secondary goal was to help the public understand that there is, in fact, an educational crisis on end of life care in our community.

A large percentage of the surveys were distributed at community medical centers. We concentrated a lot of our efforts on this for several reasons, one being that their population fit into our target demographic of aging Hispanics. At these activities, we either have educational talks, where the patients at the activity centers can ask questions, or we host activities, such as painting. We interacted with their patients and had them fill out surveys by the end of our visit.

We also distributed surveys at local community events to the general public, including the West Kendall Baptist Zoo Run, Walk to End Alzheimer's, Making Strides Against Breast Cancer Walk, Miami-Dade College Community Fairs, and Florida National University Community Fair. See image Exhibit E to reference the survey we created.

Appendix C

We had several challenges conducting our research, some expected and others unforeseen. Firstly, it was difficult for our main demographic to fill out surveys due to several different obstacles. Sometimes there was a language barrier; we had to update our survey two times to improve the translations of questions to Spanish. We also had to adjust the wording on two questions, making it easier for most to understand and to answer more accurately. In the first few months, we had a lot of surveys (90), complete with one or two questions unanswered.

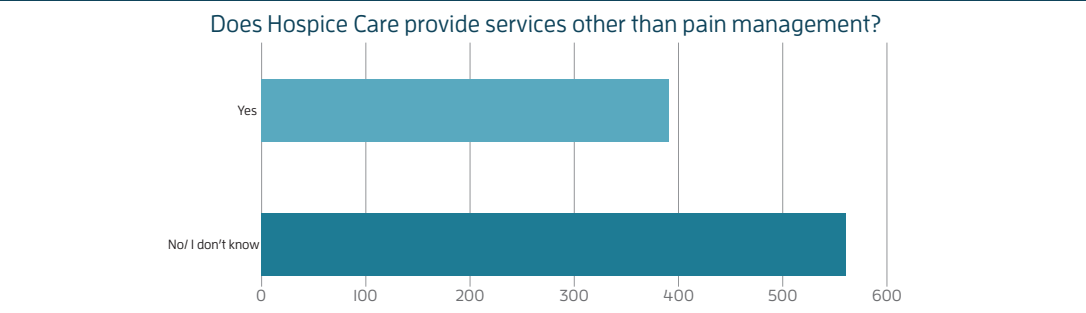
either fill out the survey for them with their answers because their writing skills were deteriorating, for example.

Furthermore, it was not as easy as we expected to obtain permission from institutions, such as churches, to survey their parishioners. They were mostly protective of their parishioners or scared to concede with fear that the archdiocese would not approve. We concluded that there was a lot of fear surrounding the subject of hospice in the Christian community.

There was also often an age barrier—we would have to

Lastly and most evidently, there is such hesitancy in this culture toward hospice care that most individuals had difficulty expressing their thoughts on the subject matter.

Exhibit D



Appendix D

Due to the budget constraints we had to work with, we decided to not go with a research company that specializes in completing investigation projects. Instead, we used our own employees, executives included, in order to move forward with our study.

As explained in page I, the hours spent on this project is where most of the dollar amount from the grant was allocated.

We relied on Survey Monkey, a resource that has 0 cost, to have the community complete surveys electronically. We spread the word through emails, our website and through our Social Media accounts. We had our Advertising/Marketing vendor, Artisan Media, design a graphic and upload it to our website, the cost was a portion of our retainer agreement. We posted it on our Instagram and promoted several times. Which amounted to, \$80. Additionally, we distributed surveys at charity and educational events. Here, we must take into account the cost to attend the events, amounting to around \$5,000, the hours spent by the individual conducting the activities or attending the event as well as gas mileage and printed collateral, which was used to help spread the word.

Dollars were also spent on the focus groups. One of the focus groups was held at our office in order to save money—around \$85 was spent on snacks, beverages, napkins, cups, etc. The other focus group was held at Riviera Country Club, in order to accomodate a different demographic - some characteristics including high income and well-educated. We spent \$150 including tax and service charges at this focus group.

Exhibit E

1. Please circle your age range:

- a. 30-50
- b. 51-65
- c. 66-80
- d. 81 and above

2. Are you Hispanic Latino?

- a. No
- b. Yes. – Print origin, for example: Cuban, Mexican, Puerto Rican, Argentinian, Colombian, Dominican, Nicaraguan, Salvadoran, Spaniard and so on.

3. What words come to mind when you hear the word "Hospice"? Please circle as many as you'd like.

- a. Dignity
- b. Poor
- c. Scary
- d. The End
- e. Comfort
- f. Sad
- g. Together
- h. Help
- i. Less Pain
- j. Death
- k. Family Together
- l. Give up
- m. Helpless
- n. Spiritual

4. If you are diagnosed with a terminal illness and have 6 months to live, how do you envision care for yourself?

- a. Seek comfort at a hospital or facility
- b. Try to heal the terminal illness with aggressive treatments like radiation and chemotherapy
- c. Seek comfort at home

5. Do you prefer...

- a. To go to the hospital when someone is very sick
- b. Receive health services at home when someone is very sick

6. Does Hospice Care offer other services other than pain management?

- a. No
- b. Yes

7. Do you know that hospice care is not only for the patient, but their family as well?

- a. Yes
- b. No

8. What is the cost of Hospice Care services?

- a. My insurance pays for it
- b. Medicare/ Medicaid pays for it
- c. The patient/family pay out of pocket

9. What is your religion/faith?

10. What is the highest degree or level of school you have completed?

- a. No Schooling Completed
- b. GED
- c. Graduated High School
- d. Graduated College
- e. After bachelor's degree (master's degree, professional degree or doctorate degree)

Conclusion

OpusCare believes that our main challenge with this ethnicity is early identification and education. Most of the Hispanic cultures do not understand the services and benefits of hospice. In fact, in this culture, one must sacrifice one's self for family which leads to difficulties with acceptance of hospice services; a family member is expected to care for their terminally ill loved one until death falls upon that person.

We have determined some of the various factors that lead to the hesitancy and general underutilization of hospice care by Hispanics. We will now be able to educate and serve them more effectively. We hope to continue studying this demographic to better serve our community. We will continue to research several elements that may influence their decisions, including: beliefs and cultural tendencies related to end-of-life care, understanding of insurance availabilities and knowledge on the continuum of services provided to both the patient and heir family.

There is no evidence to suggest that this ethnic group is dissatisfied with services once they've received them or that services are wanted but cannot be obtained. This is enough implication that social work practice research is very necessary.

Surveys Collected

