



Florida Hospice Uses Grant to Improve Outreach, Service to Hispanics

Intervention and education program for Hispanic hospice patients and their primary caregivers

SUMMARY

Staff at the not-for-profit [Hospice By The Sea](#) in Boca Raton, Fla., undertook an initiative in early 2002 to increase the number of Hispanic families they serve.

The project was part of the Robert Wood Johnson Foundation (RWJF) *Local Funding Partnerships* (LFP) national program (for more information see [Program Results](#)). It provides matching grants to support innovative community-based projects aimed at improving the health and health care of underserved and vulnerable populations.

Hospice By The Sea received an additional \$674,500 in matching grants from local funders (see [Appendix 1](#) for list of other funders).

Key Results

- Project staff increased the average number of Hispanic patients cared for daily at the hospice from 7.6 to 22.1 and increased the percentage of Hispanic patients from 1.5 percent to 5.78 percent.
- Hispanics who came to talks by project outreach coordinators showed a significant improvement in their knowledge and understanding of hospice, according to pre- and post-test results of 2,796 Hispanics who completed a questionnaire.
- In focus groups both non-Hispanics and Hispanics appeared to perceive hospice care as associated with imminent death but reacted differently to the idea of accepting this care for a family member. For more on this study of attitudes toward hospice by Hispanics and non-Hispanics, see [Assessment](#).

For a testament to the impact of hospice work (as well as more on project results), see [Results](#). For stories of two patients see [A Respite for the Family](#) and [Christmas for a Young Mother](#). For a look at the project's difficulties and approaches taken see [Challenges and Solutions](#) and [Lessons Learned](#).

Funding

RWJF provided \$493,954 in support for this project from August 2002 to July 2005.

THE PROBLEM

In 2001 the not-for-profit Hospice By The Sea served almost 4,000 patients and their families in Palm Beach and Broward Counties, Fla. However, only 1.5 percent of those patients were Hispanic—while the Hispanic population in the area was 15 percent and growing.

In 2002, the Southeast Florida Center on Aging predicted that the Hispanic population in South Florida would grow dramatically and represent 21 percent of the population by 2010 and 45 percent of the population by 2025.

According to the proposal for this project, several studies had suggested that obstacles and cultural barriers limit minorities' use of hospice services. Among those barriers are language difficulties, lack of awareness about hospice services, lack of culturally sensitive services and lack of trust in providers.

At the time of this project, Hospice By The Sea employed four specialized teams (team members included physicians, nurses, nurse assistants, social workers, clergy and volunteers) to deliver hospice care according to a patient's location. Two additional teams delivered care exclusively in nursing homes, hospitals and assisted-living facilities.

Approximately 90 percent of services provided by the hospice teams were performed where the patients resided (whether this was a house, apartment, hospital or nursing home), with the balance of care provided at Hospice By The Sea's three in-patient facilities. Teams served all patients regardless of their ethnicity.

THE PROJECT

Staff at Hospice By The Sea planned to tailor their services to better meet the needs of Hispanic patients. The project had three interventions:

- Recruit a culturally and linguistically appropriate interdisciplinary team to deliver care to Hispanic patients and their families. The team consisted of physicians, registered nurses, certified nurse assistants, social workers, spiritual counselors and volunteers.
- Conduct education and outreach to inform potential Hispanic hospice users, their families, health care providers and referral sources as well as the Hispanic community about the benefits of hospice and the specialized team for Hispanics.
- Implement a cultural competency learning program for all Hospice By The Sea staff.

To accomplish these interventions hospice staff established a program called "Abriendo Puertas" (Opening Doors). At the core of this program, hospice staff created a new Hispanic team to serve the entire hospice client area—Palm Beach County and Broward County. When a Hispanic patient or family member made a call to Hospice By The Sea, a referral nurse assigned that case to the Hispanic team (rather than to an interdisciplinary team based on the patient's location).

Hospice staff also hired two outreach coordinators, one through the Hispanic Human Resources Council in Palm Beach and one through Hispanic Unity in Broward. Both are nonprofit, community-based organizations that administer a number of programs.

Hospice staff hired an in-house coordinator to oversee the outreach as well as do her own work to raise awareness about hospice within the Hispanic community.

Other Funding

The project received \$674,500 in additional funding from local funders to match the RWJF funding (see [Appendix 1](#) for list of other funders).

RESULTS

According to project staff, the initiative achieved the following results:

- The project increased the average number of Hispanic patients cared for daily at the hospice from 7.6 to 22.1 and increased the percentage of its Hispanic patients from 1.5 percent to 5.78 percent. Before the grant started, in 2001, Hospice By The Sea cared for 72 Hispanic patients. During the three-year grant program, the Hispanic team cared for 367 Hispanic patients and their families—140 in 2004, the third and final year of the grant.

A woman who was hired as outreach director and later became the Abriendo Puertas program director had these thoughts about the project's impact, which she shared in a speech to the American Cancer Society's Palm Beach County unit in 2005:

My name is Mari Chumaceiro. I was born and raised in Maracaibo, Venezuela, and as director of the "Abriendo Puertas" program at Hospice By The Sea I have been honored to meet the most incredible Hispanic families. When you are involved with the care of a family dealing with the last days of a loved one's life, you find that emotions are very raw. These families have shared with us their struggles, their sacrifices and their successes. They thank us for all the spiritual, emotional and medical support we have offered them in their time of need, but we are the ones that are thankful because it is through their journey that we grow in our personal understanding of life, of its true meaning, of its potential.

Hospice staff also shared stories of two hospice patients and their families:

- *A Respite for the Family: Juan Fidencio Sanchez, born in Cuba, at age 84 was admitted to the Hospice By The Sea's new Abriendo Puertas Program. For more see [A Respite for the Family](#).*
- *Christmas for a Young Mother: Maria Franco de Leon, wife and mother of two young boys, had been diagnosed with breast cancer in Cuba but had been assured by her doctors there that it was under control. For more see [Christmas for a Young Mother](#).*

- People who attended talks by the outreach coordinators showed a significant improvement in their knowledge and understanding of hospice, according to pre- and post-talk results of 2,796 Hispanics who completed a questionnaire. In a pre-talk questionnaire participants scored a total of 6,881 correct answers and in post-talk they scored 15,730 correct answers, which demonstrated an overall improvement of 128.6 percent.

The same respondents also viewed hospice more favorably as a result of the talks: responses favorable to using a hospice rose from 2,280 before the talk to 4,826 afterwards.

- The outreach coordinators made direct contact with 14,743 people within the Hispanic community (4.5% of the Hispanic population) through presentations, meetings and participation in community events. Despite having difficulty organizing formal presentations—largely due to the lack of interest by churches and organizations they approached—the coordinators delivered educational presentations about hospice care to 2,796 members of the Hispanic community within 46 different organizational settings. The organizations included Hispanic Alliance, Hispanic Unity and Centro Cultural Latinoamericano.

Project staff also reached an estimated 152,870 Hispanics (46% of the Hispanic population) through paid advertisements and features about the program in local media. In addition, project staff enhanced the hospice's website to include a Spanish language component with detailed information about hospice in general and the Abriendo Puertas program in particular.

Project Director Cindy Hassett: "The educational piece of this project was a critical component. We created this team where everyone was rooted in the Hispanic culture and spoke Spanish. Once the message got out [about our Hispanic team] people felt very comfortable with it."

- Project staff produced a number of teaching tools in English and Spanish including a written patient and family handbook. Working under a subcontract, [Higher Authority Productions](#), a video production company in Miami produced three English and Spanish language informational videos about hospice.

Staff surveyed 85 families that received these tools to determine their usefulness and ease of understanding. On a 1–10 scale, with 10 being the highest, families rated the tools 8.3 for usefulness and 8.5 for vocabulary and ease of understanding.

- Some 608 Hospice By The Sea staff completed a cultural competency learning program designed by project staff. The three-hour program included modules on culture in general and specific information on the Hispanic, African-American, Jewish-American, Haitian and Jamaican cultures. All hospice employees received the training. The average post test score was 86 percent correct answers; fewer than 1 percent scored less than 76 percent.

Project staff also presented the cultural competency learning program to 109 outside organizations-such as Hispanic business organizations, churches and schools-during the grant period.

Challenges and Solutions

In a report to RWJF, project staff noted the following challenges implementing Abriendo Puertas.

- Recruiting and retaining appropriate staff for the team. The nursing shortage during the grant period (2002–05) made nursing vacancies difficult to fill. In 2003 project staff made two trips to Puerto Rico to recruit Hispanic nurses, and participated in several recruiting fairs in Dade County where the Hispanic population is large. While staff was able to fill vacancies, it had difficulty retaining nurses, in particular those recruited in Puerto Rico who had difficulty coping with the stresses of adjusting to U.S. residency while adapting to the work and unique stresses of hospice care.
- Managing a heavier workload than other teams. The Hispanic team spent a great deal of time driving because they had to cover a two-county area (other hospice care teams covered just part of a county). Team members also tended to spend much more time with Hispanic patients and their families than members of other teams.

This was in part because patients had large extended families, many of whose members wanted to be informed about the care. In addition, there is cultural importance placed on relationships and Hispanic patients expect providers to be warm, friendly and express interest in their personal life.

The project staff addressed the issue of longer visits by the Hispanic team in two ways:

- The clinical leadership made ongoing efforts to work with team members to advance the skills they needed to streamline their visits.
- Since most of their "excess" time was spent engaged in conversation, staff attempted to use volunteers and outreach coordinators as liaisons for families that seemed to have greater needs.

- Engaging community interest in hospice. Project outreach coordinators ran into major barriers when they tried to educate the Hispanic community about hospice. People did not appear interested in topics regarding hospice care, or they saw the topics as irrelevant to their lives.

According to Program Director Mari Chumaceiro, the subject of death and dying is somewhat taboo within the Hispanic culture where people prefer not to speak about aspects of the future that are potentially dire. Hispanics can also be superstitious believing that talking about death can bring it about.

In the final year, the staff focused on educating physicians who serve a large number of Hispanic patients.

- Bringing patients and families into hospice care earlier in the terminal phase. One of the challenges that face all hospices is a decreasing length of stay. Although more people are using hospice, most enter the program in the last days of a patient's life, rather than the last months when hospice care can provide the most benefits for patients and families. In fact, the median length of stay in the hospice program for the project's Hispanic patients declined from 13 days in 2002 to 10 days in 2005.

The staff addressed the issue by educating physicians who treat Hispanic patients about services that hospice can provide that physicians typically cannot (such as daily nursing care). They also began working with another team within the Hospice By The Sea organization that helps patients transition between non-hospice home health care and hospice. Staff hoped that those team members could identify Hispanic patients earlier in their illness and refer them to hospice, which could lead to an increased length of stay.

- Establishing stronger connections within the Hispanic church community. RWJF and *Local Funding Partnerships* staff emphasized the need to include the Hispanic faith community in the project's effort. While the staff made significant efforts to reach these churches, few showed interest in the work.

ASSESSMENT

The hospice staff subcontracted with *SRA Research Group*, a market research firm in Jupiter, Fla., to explore attitudes toward hospice, and particularly toward Abriendo Puertas by conducting three focus groups in Boca Raton, Fla., during September 2004.

The focus groups—of eight to 10 participants each—comprised:

- Hispanic family members of current or past hospice patients.
- Hispanic prospective users of hospice.
- Non-Hispanic prospective users.

SRA Research Group also conducted telephone interviews with 10 local physicians who treated a large number of Hispanic patients.

ASSESSMENT FINDINGS

In October 2004 SRA Research Group staff reported these findings to project staff:

- Non-Hispanics and Hispanics perceive hospice care as associated with imminent death, but react differently to accepting this care for a family member.
 - Non-Hispanic prospective users of hospice, while somewhat fearful of hospice, are much more accepting of it than Hispanics.
 - By comparison, Hispanics are very resistant to hospice due to cultural differences and lack of awareness of it from their ancestral homes.
- Culturally, admitting a family member into hospice is seen as tantamount to abandonment among many Hispanics.
- Hispanics associate the word hospice, in connection to a loved one, as repulsive. In their home countries, "hospicio" is negatively associated as a place where either abandoned, poor, elderly people or orphans are cared for.
- Physicians are the most trusted source of information about hospice care for Hispanic and non-Hispanic prospects.
- All groups-Hispanic prospects, non-Hispanic prospects, Hispanic users and physicians-need more education about hospice.
 - Physicians feel they are knowledgeable about hospice and are the acknowledged gatekeeper. However, many lack a solid understanding due to lack of education and training about end-of-life care in medical school.
- Physicians, as well as Hispanic users, stressed that the onus of getting into hospice late is on the patient and family, not the physician.
- Female family members generally play a key role in the transition into hospice.
 - Physicians and the Hispanic users of hospice concur that the patient is rarely part of the decision process. Families, in particular, want to "protect" their loved one by keeping bad news away from them.
- Non-Hispanics tended to focus on both emotional and practical issues of using hospice while Hispanics concentrated solely on the emotional and spiritual aspects.
- The services offered by Abriendo Puertas provide value to the Hispanic community. The positive aspects associated with the program include:
 - A bilingual team that communicates in Spanish.

- Care that is delivered with warmth.
 - Availability of team members 24 hours a day, seven days a week.
 - Professionally delivered pain management.
 - Guidance in the final steps of the dying process.
- Most potential hospice users and local physicians are not aware of the Abriendo Puertas program.

LESSONS LEARNED

1. **Engage physicians treating Hispanics if you want to increase hospice use by Hispanics.** Project staff underestimated the role of the physician as the primary decision maker regarding Hispanics' decision to use hospice. At the start of the project, staff placed almost all of the outreach efforts on direct education for members of the Hispanic community. Then, the project's focus groups identified physicians as the primary influence on Hispanic patients' or families' decision to enter hospice—although half of physicians interviewed had no knowledge of the Abriendo Puertas project.

In response, project staff identified 215 physicians with a local Hispanic patient base of greater than 25 percent and targeted those physicians for educational in-service presentations about hospice and the Abriendo Puertas program. According to project staff, this strategy appeared to be more effective. (Project Director/Hassett)

2. **Offer Spanish language capabilities at all points of contact when serving a predominantly Spanish-speaking population.** In the beginning, project staff did not realize that the Hispanic patients and families they were serving would need contact with a Spanish-speaking team member from their first encounter (referral) to their last (bereavement counseling), and that telephone inquiries should be handled in Spanish.

Staff concluded that for an organization to serve a population with language barriers they must identify all the potential points of contact during the planning phase to ensure a seamless delivery of culturally and linguistically appropriate services. (Project Director/Hassett)

3. **Avoid quick fixes to problems like the nursing shortage. In this case, hospice staff traveled to Puerto Rico to hire nurses.** They quickly learned that nurses recruited from outside the continental United States face numerous acculturation challenges, both to this country and to hospice work. Of the six nurses hired in Puerto Rico, only one was still with the team less than two years later. (Project Director/Hassett)
4. **Pay attention to the time commitment necessary when working with the Hispanic community.** Project staff at first underestimated the importance of relationship building and information sharing with patients' large extended families

when working with Hispanic patients. Any organization that attempts to provide culturally sensitive services to the Hispanic community needs to pay attention to these two factors and make time for them during service delivery. (Project Director/Hassett)

5. **Look for unconventional ways to get an uncomfortable message out to a community.** In this case, hospice outreach staff made presentations to Hispanics taking English language classes. The presentations provided the coordinators with a captive audience and the students with new vocabulary and information on hospice and health care. (Project Director/Hassett)

AFTERWARD

As of March 2006, the Abriendo Puertas hospice program was continuing, its Hispanic team sustained through reimbursement revenues from Medicare, Medicaid and private insurance.

In 2004, Hospice By The Sea staff started an outreach program aimed at African Americans with funding from two local philanthropies, the Allegany Franciscan Foundation and the Freimann Healthcare Initiative.

Hospice By The Sea has continued its cultural competency learning program for new employees as part of its ongoing orientation and training program for them.

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APPENDIX 1

Local Funders

DONOR	AMOUNT
Quantum Foundation, West Palm Beach, Fla.	\$300,000
Allegany Franciscan Foundation, Clearwater, Fla.	\$140,000
Frank Stanley Beveridge Foundation, Boca Raton, Fla.	\$50,000
Palm Healthcare Foundation, West Palm Beach, Fla.	\$50,000
Harry Maus, Boca Raton, Fla.	\$30,000
Walter and Adi Blum Foundation, Palm Beach, Fla.	\$30,000
Harold and Mary Ann Perper Foundation, Boca Raton, Fla.	\$25,000
Community Foundation of Broward, Ft. Lauderdale, Fla.	\$11,000
Schmidt Family Foundation, Boca Raton, Fla.	\$10,000
Russek Foundation, Boca Raton, Fla.	\$10,000
Mr. and Mrs. Meyer Eisner, Coconut Creek, Fla.	\$10,000
Sun-Sentinel Diversity Venture Fund, Ft. Lauderdale, Fla.	\$8,000
Diana Wasserman-Rubin, Ft. Lauderdale, Fla.	\$500
Total	\$674,500

APPENDIX 2

A Respite for the Family

Juan Fidencio Sanchez, a native of Cuba, spent much of his adulthood in the United States where he worked as a business administrator until his retirement in 1985 at age 67. Less than two years later, he was diagnosed with Parkinson's Disease. In August 2002, at age 84, he was admitted to the Hospice By The Sea's new Abriendo Puertas program.

While Juan was fluent in English, as he became more ill he spoke only in Spanish and thought more of his days in Cuba. With the Spanish-speaking hospice team, he could communicate in the language most comfortable to him about a culture that they understood. They were delighted to hear his jokes and Cuban songs.

The team members also understood the impact of "la familia" in the Hispanic community where there is a strong dependence on the nuclear as well as the extended family.

Hispanics are proud and honored to take care of their loved ones at home. In Juan's case, his wife Amanda helped care for him, and his daughter Silmar moved in with her parents to help as well. When his care began more difficult, his cousin's wife Triny came to help.

But the Abriendo Puertas team, which had developed a close relationship with Juan and his family, noticed that the family was increasingly stressed and exhausted. Juan's wife became so ill that she had to be hospitalized twice. To add to the pressure, Triny had to return to her home for a family emergency.

Team members told the family about the benefits of respite care, in which Juan would stay at one of the hospice care centers and the family would receive a break from the all-consuming demands of care. The family agreed and the respite stay provided the relief that Juan's family needed. When he returned home, family members, along with the hospice team, were able to care for him until his death in October 2004.

APPENDIX 3

Christmas for a Young Mother

Maria Franco de Leon was a wife and mother of two young boys in 2002 when she and her husband Eduardo arrived in the United States as refugees from Cuba. Maria, age 35, had been diagnosed with breast cancer in Cuba but been assured by her doctors there that it was under control.

She and her husband were thrilled to arrive in the United States with the promise of a new life. But just one month after their arrival, Maria had to seek hospital care for complications of her cancer. She learned that, far from having it under control, her cancer had progressed to the point where she only had a few months to live.

One of the outreach coordinators for Abriendo Puertas made a presentation at the school attended by Maria's children. A teacher took her aside and asked that she talk to Maria about the hospice program.

Soon, the team was providing care to Maria and her family. The family did not yet speak English and Eduardo had to stop working construction to take care of his wife. Having the hospice team there helped the family navigate the health care system and provided Eduardo with a chance to work again.

One of Maria's wishes was to celebrate Christmas—something she had never really been able to do in Cuba. The hospice team arranged a festive celebration, complete with a Christmas tree, decorations, presents for the boys and the traditional roasted pig.

The celebration delighted Maria, who held on so that she could be part of her family's first Christmas in the United States. Not long after, she became even sicker. She asked to be admitted to the hospice care center so that her boys would not see her suffer. She died in January 2004.

After her death, the hospice provided bereavement support and brought the boys, age 6 and 8, to its "Camp Good Grief," which is a camp for children who have lost a loved one. Eduardo said that he was grateful to the hospice team for their support, service and compassion during such a difficult time.

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Audio-Visuals and Computer Software

Educational Outreach Video, an eight-minute videotape in Spanish and English introducing the benefits of hospice services for patients with life-limiting illnesses and their families (includes testimonials by families about the benefits of hospice as well as professionally moderated segments highlighting the process one goes through in using hospice services). Miami: Higher Authority Productions, 2002.

Patient and Family Video, a 10-minute videotape in Spanish and English introducing hospice services to patients and their families that have entered a hospice program (includes hospice care overview and addresses basic caregiver concerns). Miami: Higher Authority Productions, 2002.

A Lifeline for Home Caregivers, a 38-minute teaching videotape, in Spanish and English, detailed the essentials of caring for a terminally ill patient at home. Miami: Higher Authority Productions, 2002.

Survey Instruments

"Abriendo Puertas Educational Outreach Survey," Hospice By The Sea, fielded September 2002 through July 2004.

Grantee Websites

www.hbts.org. English language website created to facilitate access within the Hispanic community to information about hospice care and the services of a culturally and linguistically specialized hospice patient care team. Boca Raton, FL Hospice By The Sea, 2002.