



LATINO

OUTREACH GUIDE

Caring Connections
a program of the
National Hospice and Palliative Care Organization



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See the Appendix section of this Guide to download PowerPoint® templates for presentations that you can adapt for your community education needs.





LATINO OUTREACH GUIDE

I. Overview

As the number of Latinos living in the United States continues to increase, it is vitally important for hospices and end-of-life coalitions to expand outreach and programmatic efforts to ensure Latinos receive quality end-of-life care. NHPCO's Caring Connections has created a Latino Outreach Guide to provide you with ideas and resources to guide your outreach efforts. We have included resources that are in English and Spanish to help you reach out to Spanish-speaking individuals and communities.

In 2005, Hospice Caring Project of Scotts Valley, CA, formed a Latino community partnership called "Mensajeros de Confianza" ("Trusted Advisors") to engage local health and human service professionals in a conversation about end-of-life care for the Latino population. The Latino Outreach Guide highlights this partnership as a model for hospices and coalitions who would like to expand their community outreach to the Latino population.

Please refer to the 'Key Terms for Latino Outreach' document which includes phrases or words you may encounter when interacting with the Latino population. While the Latino community in this country is composed of many different cultures and nations, most Latinos in the United States have Mexican roots. Therefore, we have emphasized Mexican culture and heritage in these materials, while recognizing that there will be variations in many communities. As with all successful outreach efforts, the characteristics of the community or region should always be taken into account.

As you begin to implement your outreach activities, please feel free to adapt the resources included in the Outreach Guide to serve your specific needs, however, we ask that you credit Caring Connections. You can contact us at caringinfo@nhpco.org and we will provide you with the text for your credits since our materials are copyrighted.



II. Caring Connections Latino Focus Groups: Key Findings

In May of 2006, Lake Research Partners (LRP) conducted four focus groups with Latinos for Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO). These focus groups were part of a broader study aimed at informing NHPCO's outreach and communication efforts to diverse racial and ethnic communities. Since the goal of community outreach is to engage people in end-of-life discussions before they are faced with a crisis, the focus groups were conducted with middle-aged Latinos who had not lost a loved-one in the recent past and had never had a life-threatening illness or injury. Two groups were conducted in Spanish in Houston, and two were conducted in English in Los Angeles.

The following are some preliminary recommendations from the focus groups conducted in May 2006.

ADVANCE CARE PLANNING

Although the majority of Latinos are unfamiliar with the concept of advance care planning, the subject resonated with the Latino community and participants felt basic education materials would be helpful. Latinos, more than other Americans, are more likely to have planned for what will happen after death. They may have made funeral plans, purchased life insurance, or written a will. Participants discussed the importance for family members to come to consensus about the care of loved ones.

A majority of focus group participants said they personally would not want to be kept alive on life support, but are more divided about withholding life support from a loved one. Brief, descriptive resources on end-of-life topics including artificial nutrition and hydration are needed.

END-OF-LIFE CAREGIVING

A better understanding of the term "caregiver" is needed within the Latino community. For many Latinos the term "caregiver" implies a professional role such as that of a nurse or home-health-aid. Family caregivers may not identify themselves as such since caring for family members at home is part of their culture and tradition.

HOSPICE

It is important to emphasize to Latinos the importance of family in hospice care. Some Latinos have not heard of hospice, and many who have do not know much about it. Some equate hospice with nursing homes. Nursing homes have negative connotations in Latino families because they go against the cultural tradition of the family providing care for the sick and elderly. It was with this focus group that the term "compassionate care" was found to be more effective than "hospice."



III. Hospice Caring Project's "Mensajeros de Confianza" Community Partnership Profile

Hospice Caring Project (HCP), a hospice provider that serves the Santa Cruz area in California, raised \$170,000 from three funders for an 18-month "Challenge of Change" initiative to:

- ◆ Learn about preferences involving terminal illness, death, and bereavement for the local Latino community, and
- ◆ Develop a plan for lessening barriers to hospice that will enable HCP to successfully deliver end-of-life care to this community.

It took a significant amount of time for HCP to gather information from the local community, create and expand community partnerships, and build awareness about end-of-life issues in the local Latino community.

From their experience, HCP found that:

- ◆ It is imperative that culturally-relevant practices and procedures are integrated into all services.
- ◆ A strong internal committee and a strong external advisory committee must support the project.
- ◆ To best identify service barriers and develop the means to remedy them, the target community must be involved in your organization as a partner.

There were several structural changes that HCP made in order to achieve their objectives. **Specifically, HCP:**

- ◆ Hired bilingual/bicultural clinicians and staff when possible.
- ◆ Created a new bilingual/bicultural Latino Community Liaison position to coordinate outreach. *A high school educated Latina woman was hired who brought her ties to the community (15 years working at a local clinic) and the right personal traits (an outgoing personality, compassion, and strong communication skills) to the position.*
- ◆ Actively recruited Latino leaders to serve on HCP board.
- ◆ Provided cultural competency training sessions for all HCP staff.
- ◆ Incorporated goals and objectives for serving the Latino community into their strategic plan ensuring a level of accountability to the Board of Directors and the management team.
- ◆ Integrated knowledge from research conducted with the Latino community and gained from community partners into day-to-day operations to ensure that all HCP staff work together to provide compassionate end-of-life care to Latinos.

COMMUNITY PARTNERSHIPS

HCP recruited three key partners (a non-profit community health clinic, an umbrella group for Catholic charities, and an organization that supports women with a cancer diagnosis) as their primary collaborators. HCP established a ‘Memorandum of Understanding’ with these agencies, agreeing to share knowledge, resources, and provide HCP with referrals to Latino families in need of hospice and bereavement services.

MENSAJEROS DE CONFIANZA (“TRUSTED ADVISORS”) ADVISORY COMMITTEE

The three original partnership organizations served as founding members of the Mensajeros de Confianza, an advisory committee that grew to include 28 organizations of diverse size and purpose who serve the local Latino community; a majority of members are Latino. Establishing the three initial partnerships gave credibility and importance to the development of Mensajeros de Confianza, and their commitment encouraged others to attend, as did familiarity with HCP’s Latino Community Liaison from her previous affiliation with the local health clinic.

Through its monthly meetings, Mensajeros de Confianza, has become an important resource for HCP to engage the larger community of local health and human service professionals in a conversation about end-of-life education for the Latino population. Importantly, Mensajeros de Confianza evolved into a community forum for addressing a wide range of Latino service barriers affecting various health and social service disciplines. A diverse group of organizations, from the media, business, and political communities, as well as traditional service providers, are fully engaged in supporting each other, educating each other in their respective community roles, and discussing how they can work together to ensure that all community members are equally served.

FAMILY INTERVIEWS

To begin their focus on Latino families, the Latino Community Liaison at HCP and an experienced bilingual counselor conducted 8 interviews with Latinos whose family members had previously used HCP’s services. Through the interviews, HCP gained information about end-of-life beliefs, concerns, and traditions.

Interviewees made it clear that bilingual and bicultural staff made a significant contribution to their hospice experience. They described cultural nuances such as the importance of family unity, and family members visiting from their home country at the end of life, in which case travel and immigration assistance is very important. All interviewees discussed the importance of the El Novenario ritual, common in many Latin American countries, where the body of the deceased is held in the home for a minimum of 24 hours.

Lastly, interviewees felt that an important way to reach the Latino community is through Spanish language television, radio, and diverse print media.



INTERNAL WORKGROUP

In order to ensure that HCP incorporated outreach to Latinos throughout its structure, an internal workgroup was formed, composed of the Executive Director, Director of Clinical Services, Director of Volunteer Services, Latino Community Liaison, bilingual/bicultural nurses, home health aides, and a bilingual social worker who met monthly to discuss systems issues related to serving Latinos.

The presence of bilingual/bicultural employees was very important because they are the first to know if an approach that HCP uses is being received well or should be reconsidered. The Internal Workgroup also addressed many of the issues that arose at the Mensajeros de Confianza Advisory Committee meetings and contributed to the development of community outreach materials. In addition, the internal workgroup discussed how to best serve Latino families using HCP services.

CULTURALLY-RELEVANT BILINGUAL MATERIALS

Another important component of the outreach HCP has done has been retaining a part-time Spanish language consultant for the purpose of translating HCP admittance forms and other appropriate documentation, translating recruitment information targeting bilingual/bicultural personnel and developing a Spanish-language HCP brochure and accompanying outreach materials. This consultant worked closely with the Latino Community Liaison and the other members of the internal committee geared towards Latino initiatives.

Community research and family interviews revealed that materials describing HCP services could not just be translated; they needed to be “transcreated” (translated to ensure that they make sense both literally and culturally) to address the concerns and end-of-life traditions of the Latino community. Members of the Mensajeros de Confianza advisory committee contributed to a review and adaptation of the materials, drawing upon their own agencies’ experiences and their bicultural backgrounds. HCP created two brochures, one in English and one in Spanish, to introduce hospice care and the ways in which HCP can help at the end of life. Additionally, the internal translation group created a “fotonovella” for low-literacy Latinos, describing hospice services through photographs and simple text.

BUILDING AWARENESS

Awareness about end-of-life choices is building in the Latino community that HCP serves. The ongoing support of the Mensajeros de Confianza advisory committee and the presence of bilingual, bicultural staff members at community events have gradually raised the profile of HCP and end-of-life care in the community. The experience of HCP emphasizes that change is gradual and building trust with a Latino community takes time. The ongoing, consistent efforts of HCP have made community partnerships flourish and a vital discussion regarding service barriers facing the Latino population has ensued.

At the conclusion of the eighteen month project HCP is witnessing a new direction in their Latino community— there is greater awareness, collaboration and interest in end-of-life education. HCP is being invited to conduct in-service presentations, participate in community events and present their expertise in community forums previously unreceptive or unknown to them.

For example, in April 2006, HCP hosted a representative from the Mexican Consulate at the Mensajeros de Confianza meeting. The rich discussion focused on end-of-life issues including the transportation of bodies back to Mexico and the challenges of bringing family members from Mexico to be with their loved ones at the time of death. Members of the Mensajeros de Confianza have expressed interest in inviting the INS (Immigration and Naturalization Service) to attend a future meeting to help build awareness and relationships that can benefit the community.

LATINO OUTREACH PLAN

Using the findings from the family surveys and the Mensajeros de Confianza, HCP developed and implemented a written 'Latino Outreach and Educational Plan' designed to meet specific goals, objectives, and outcomes (which is located at the end of this section).

Over 250 Latinos have received information directly about HCP services through speaking engagements and interactions with HCP staff and volunteers at community events and an advance directive workshop. Community events where HCP has had a presence include a Mexican Independence Day celebration, a local woman of the year award, and Latino business association meetings.

LESSONS LEARNED

HCP feels that even with the significant internal changes they adopted to serve the Latino community and the comprehensive approach they have taken towards community outreach with Latinos, the targeted community must be ready to learn about end-of-life issues to truly improve access to care. It is important to build trust as well as awareness in a community and this process often happens one family at a time. HCP has acknowledged past weaknesses in serving the Latino community and made a commitment to learning.

Through this initiative, HCP has brought awareness to the fact that many Latinos do experience the benefits of hospice care. By fostering a continual and compelling conversation about the end of life with the Mensajeros de Confianza, HCP has broadened and effectively increased their visibility with community agencies, leaders, health and human service professionals and organizations serving the Latino community. Through these meetings, HCP has begun to develop a safety net of community resources that will encourage Latino families to seek hospice, and also help our larger community of service providers enhance their methods of service within the community.

For more information contact: Hospice of Santa Cruz (*formerly called Hospice Caring Project*)
831.430.3000 ♦ www.hospicesantacruz.org





Hospice Caring Project's Latino Outreach and Educational Plan

The following plan highlights Hospice Caring Project's planned outreach services to the Latino community.

A three-year agency strategic plan, adopted in August 2005 guides the daily operations of HCP services to the Latino community. The following measurable objectives and outcomes of the plan are reviewed and reported to the board on a monthly basis. Additionally, methods for increasing Latino share of census and outreach are reviewed quarterly at a quality assessment and improvement (QAandI) meeting of management and key staff.

- ◆ Increase Latino share of census by 10% per year to 30% in 2008.
- ◆ Increase the number of Latino volunteers 800% by 2008.
- ◆ Increase bilingual personnel to meet the needs of the Latino patients.

Public Events

Informational Tables: Latino Community Liaison, Health Educator and volunteers to attend events and create awareness of HCP and end-of-life services.

- ◆ Cinco de Mayo – May 5th (annual) – All Day Event
- ◆ Mexican Independence Day – September 16th (annual) – All Day Event
- ◆ Hospice Foundation teleconference – April (once a year) – All Day Event
- ◆ Cabrillo College Wellness Outreach at Watsonville Campus – (twice a year during Fall and Spring semesters) – All Day Event”
- ◆ National Hospice Month (November) – Display at Watsonville Hospital
- ◆ Watsonville Farmers Market (twice a year) – Half Day Event

Major Public Event: Day of the Dead – November 1st. Event will be held in collaboration with the Mensajeros De Confianza.



Educational Presentations

In-service presentations to professional staff conducted annually

Clinics:

- ◆ Salud Para La Gente (Staff and MD's)
- ◆ La Plazita Medical Clinic (All Staff)
- ◆ Clinica del Mar (All Staff)
- ◆ Clinica Familiar Costa Central (All Staff)

Hospitals:

- ◆ Watsonville Community Hospital
- ◆ Santa Cruz Dominican Hospital
- ◆ Salinas Valley Memorial

Agencies:

- ◆ WomenCARE
- ◆ Catholic Charities

Community:

- ◆ Migrant Regional Parent Meeting
- ◆ Latino Business Association (Local Business and service agencies)
- ◆ St. Patrick's Church
- ◆ Assumption Church
- ◆ Our Lady of Christians

Media:

- ◆ Educational Presentations bi-annually
- ◆ TV (Channel 67)
- ◆ Radio (Telefutura)
- ◆ Ads and press releases as needed relating to events:
- ◆ Santa Cruz Sentinel
- ◆ Registered Pajaronian
- ◆ La Ganga

Networking and Collaborative Organizations

- ◆ Mensajeros de Confianza Advisory Group (six per year)
- ◆ Pajaro Valley Chamber of Commerce
- ◆ Latino Business Association Meetings (monthly)
- ◆ Mixers (three per year)



IV. Tips for Building Partnerships with the Latino Community

BUILD TRUST

One of the most important things that any organization must do when working with a cultural community for the first time is to build trust. Gaining the trust of a community takes time. Building trust needs to be your main goal in building partnerships. Below are suggestions that can help your organization or coalition to build trust with the Latino Community.

RECRUIT A LIAISON TO THE COMMUNITY

One of the cornerstones of your outreach needs to include the involvement of a bilingual, bicultural person already well connected to the local Latino community. Think broadly about who might be the best person for your outreach—focus on the person and his or her qualities and skills, such as his or her ease of working with people, rather than only on traditional qualifications, such as education level. It is important to assess his/her credibility with and access to the people you are trying to reach. Be sure the person you select is respected in the community.

GET FEEDBACK

Seek input from your local Latino community and interview families who have received hospice services and learn about their experiences. In order to successfully provide services to Latinos, it is essential for the members of your Latino community to describe their experiences with hospice and voice their desires and concerns about end-of-life care.

Below is a sample of questions that Hospice Caring Project used for their family interviews:

- ◆ *How did you learn about Hospice Caring Project? From someone at the hospital, a friend or family member?*
- ◆ *What did you think when you first heard about hospice?*
- ◆ *How did the people from hospice help?*
- ◆ *What did you and your family most need when your loved one was in the last stage of her/his life? Personally, practically, spiritually? And afterward?*
- ◆ *What are the main traditions in Mexico when someone dies?*
- ◆ *Which of these traditions do you consider that hospice should be aware of to better serve your family?*
- ◆ *What are some ways to take the message of hospice into Mexicano/Latino communities?*
- ◆ *Would you be willing to speak of your experience with hospice to help us tell others about our services?*

ESTABLISH CLEAR GOALS

After you have gathered information from your community, develop clear goals for your outreach. Once you have collected feedback from the Latino community, goals should be formulated and clearly stated to serve as a guide for your outreach process. Incorporate your goals for engaging the Latino community to the strategic plan of your organization or coalition. This guarantees a long term commitment to cultivating relationships with and serving the Latino community. Having the goals in the strategic plan can help to ensure adequate time and attention is given for program development and funding.

CREATE AN ADVISORY COMMITTEE

Create formal relationships with a few key service providers to build bridges to the people who need your services. In order to do Latino outreach, form an Advisory Committee composed of community stakeholders who will assist you in the development of culturally competent services. To initiate this process, focus first on a few key service providers who will be most important to your work.

Since most service providers, especially the ones that would be most influential and therefore the best partners, are very busy and their time is valuable, consider drawing up a formal 'Memorandum of Understanding' and setting aside a certain amount of money for each organization for their services if possible. (*See sample located at the end of this section.*) A formal relationship can be the key factor to ensure your Advisory Committee has a strong start, as these organizations will be your initial Advisory Committee members.

Recruit community stakeholders:

Invite organizations and influential individuals to also join the Advisory Committee after you have initial members in place. Do your homework to learn who is influential in the community and then meet with potential members to explain what you are trying to accomplish. Individuals who may be influential in the Latino community include clergy, those who work with migrant farm workers, union organizers, and local Latino businesses. Other stakeholders include health and human service organizations, the political community (local town and county representatives) and possibly a local foreign consulate (example: Consul of Mexico).

Make meetings meaningful:

The function of the Advisory Committee includes encouraging and accepting their advice for your outreach, reciprocal learning among committee members and enabling the members to collaborate to better serve the community as whole. Advisory Committee meetings need to be a time to gather input from committee members and to welcome advice that they have for various aspects of your outreach activities which can include questions about terminology to the best venues for outreach activities. It is important to report back to the committee about ways in which their advice and input has been used to shape different aspects of the community outreach your hospice is doing.



Meetings are also an excellent time for committee members to learn from each other, and to have time to discuss their own organization. It may be the case that bringing people together around end-of-life issues serves a larger community purpose, if there has not already been a way for service providers for the Latino community to collaborate and create a better network. The more that the attendees are gaining from the meeting, the stronger their commitment to the Advisory Committee will be. Therefore, looking at the wider community picture should benefit the Committee and your organization or coalition. (See 'Initial Meeting Agenda' located at the end of this section.)

The following are suggestions from Hospice Caring Project on how to conduct a successful advisory committee meeting:

- ◆ *Provide food.*
- ◆ *Provide a convenient meeting time and place. Ask the group to decide on frequency of meetings.*
- ◆ *Meetings need to be participatory as well as educational.*
- ◆ *Have 1 or 2 service providers give a brief presentation about their organization during each meeting. If participants are comfortable doing this, ask them to give a quick update of what is currently a focus in their organization at the beginning of every meeting.*
- ◆ *Leave time for networking amongst attendees.*
- ◆ *Always have at least one subject that you want advice on. Follow-up on past issues where advice has been given and then let them know what you have done that incorporates their input.*
- ◆ *Convey as often as possible to the Committee that their expertise and participation is a valuable asset to your organization or coalition.*
- ◆ *Send out minutes to those who attended and those who could not attend.*

Stay connected:

Email can be a very effective means of communicating and staying connected with Advisory Committee members between meetings. Asking advice on the use of a Spanish term, or letting members know that your organization had a successful experience at an outreach event can demonstrate the commitment that you have to using the Advisory Committee and learning from its members. Careful use of an email listserv can help to reinforce your organization's commitment and serve as another way of building trust.

FOCUS ON RELATIONSHIPS, NOT PROJECTS

In our goal-oriented society, it is all too easy to focus on project goals. One of the gifts that the Latino culture provides to us is the reminder to focus on relationships. Meaningful relationships always provide the best results. So when you are getting too stressed about your all work-related projects, sit back and enjoy your new friends from a different culture. This is the best guarantee to successfully build partnerships and implement outreach activities with the Latino community.

Challenge of Change Initiative

MEMORANDUM OF UNDERSTANDING BETWEEN HOSPICE CARING PROJECT AND [PARTNER]

Hospice Caring Project is developing relationships with Mensajeros de Confianza (trusted messengers within the Latino community) to help reach our goal of creating culturally-relevant end-of-life information and services to the Latino community. [Partner] agrees to enter into a collaborative agreement with Hospice Caring Project (HCP) by providing the following services for the Challenge of Change Initiative.

- ◆ Follow-up counseling as needed for focus group participants: HCP is conducting focus group meetings with up to twelve families who have received HPC services. Family members may experience feelings of grief as a result of these meetings and will be encouraged to call the HCP program coordinator if needed. If the coordinator assesses that counseling is needed, she will make a referral to [Partner]. [Partner] will provide up to three counseling sessions at no charge to the client.
- ◆ Review of translated materials: [Partner] will review translated materials (postcards, brochures, letters), consulting on cultural relevance of materials presented to the community.
- ◆ HCP and [Partner] will partner to present in-service training on end-of-life care once during the year.
- ◆ A system will be developed and documented for referring appropriate [Partner] families to HCP when appropriate.

FUNDING:

Hospice Caring Project will allocate \$_____ for services provided during the initial year of the grant cycle, and an additional \$_____ during the second year.

Ann Carney Pomper, Executive Director
Hospice Caring Project Santa Cruz
Date:

[Representative/Partner]
Date:



**Mensajeros de Confianza Advisory Group
Hospice Caring Project Challenge of Change Program**

INITIAL MEETING AGENDA

- I. Welcoming by Ann Pomper, Executive Director (3 minutes)**
- II. Goals and Objectives of meeting - Lupe Mendoza, Latino Community Liaison (2 minutes)**
- III. Self Introductions – Everyone (15 minutes)**
- IV. Hospice Caring Project Services- Salima Cobb, Professional Liaison (10 minutes)**
- V. Challenge of Change Program - Lupita Mock, Registered Nurse/Lupe Mendoza, Latino Community Liaison (15 minutes)**
 - a. How did Challenge of Change Program Start and Why?
 - b. Roles and Responsibilities of External /Internal Groups - Mensajeros de Confianza/Hospice Staff
 - c. Goals/Objectives/Accomplishments of Program
- VI. Update on Latino Family Interviews – Cathy Conway – Development Director (10 minutes)**
- VII. Mensajeros de Confianza Advisory Group - Everyone (45 minutes)**
 - a. What has worked in your community?
 - b. What can we learn from you?
 - c. How do you want to be involved in helping Hospice Caring Project build their capacity to serve the Latino Community?
- VIII. Develop Meeting Calendar for Mensajeros de Confianza Advisory Group (3 minutes)**
- IX. Closing Remarks – Ann Pomper/Lupe Mendoza, Latino Community Liaison (2 minutes)**

V. Outreach Strategies and Activities to Engage the Latino Community

The following are examples of outreach strategies and activities that were used by Hospice Caring Project (HCP) and others to engage with the Latino community around end-of-life issues.

FOTONOVELLA (ALSO CALLED “PHOTONOVELA”)

Create a fotonovela to promote hospice, advance care planning or other topics. A fotonovela is a small booklet in picture story form with narration which can be used to carry a message or educational information. A fotonovela uses photos rather than drawings to illustrate a story. In Mexico, the fotonovela is a popular way to convey information about things like social norms and health messages, and is an easy way to communicate with people who have limited literacy skills.

Hospice Caring Project created a fotonovela that demonstrates hospice services in action and provides information about how to refer someone to hospice care. The story begins outside the church after mass, where two women friends are talking. One woman asks her friend, the wife of a very sick man, “How are you doing?” The woman tells her story and her husband’s, and then her friend reacts by explaining what hospice is. The wife of the sick man later calls a hospice. The fotonovela illustrates the process of becoming a hospice patient, receiving services, the experience of the family and the support hospice offers following the death of the family member. Most of this is conveyed in pictures and there are also a few sidebars with information.

ENGLISH AS SECOND LANGUAGE (ESL) CLASSES

Make connections with local ESL programs. They often have guest speakers who come to explain a particular community organization. Many students in ESL programs have recently arrived from another country, are a range of ages and have a variety of experiences. Many stories are told during a class and therefore it is a great time to spark a discussion about community resources regarding family caregiving, hospice, advance care planning and grief support.

The presentations are done in English but since students are not yet fluent in English some things are explained in Spanish to ensure that the class completely understands the information. ESL instructors want to encourage students to practice their English skills and further their comprehension, but also want to make sure the presentations are worthwhile for all.

Students are learning English in order to get jobs, and many have a special interest in healthcare jobs. They will go on to work in radiology, dentistry, hospitals, and skilled nursing facilities. These new healthcare

workers often become resources for their families when they need knowledge on health related issues. By speaking to people soon after their arrival in America, you can plant seeds about hospice—educating them about a service available in their new country, and potentially interesting them in working in end-of-life care.

MIGRANT WORKERS

Many Latinos in the United States are migrant workers, especially in rural areas. Often migrant workers speak only Spanish and have sub-standard access to health care and education. Usually, you will be able to find local social service programs that have been developed to assist them. By partnering with these established programs you will be associated with a trusted entity and therefore have an easier time educating the workers about end-of-life care. Many migrant workers are young and have school-aged children. Some school systems have designated teachers or administrators who work with migrant parents who are new to a school system and may require special attention as they enroll their children. In the experience of Hospice Caring Project, meetings of migrant parents organized by the school are especially well attended, and are a good place to reach people with informal presentations and literature.

SPANISH-LANGUAGE NEWSPAPERS AND RADIO

Many Latinos receive information about local services through Spanish-language newspapers. Many Spanish-language newspapers are not daily papers—they may only be weekly, biweekly or monthly. Contact Latino service providers in your area to discover which publications might provide a free or reduced-rate advertisement on end-of-life issues. Because of the extensive healthcare needs of the Latino community, some newspaper publishers may have a policy of allowing health organizations or non-profit groups to advertise for free.

Radio is another good way to reach the Spanish-speaking population. Even if your area does not have a regular radio station for Spanish-speakers, you may find that there are one or more low wattage radio stations in your area that are important to the Latino community. A public service announcement could be an excellent way of reaching this audience, and again, it is likely that the stations welcome PSAs from health organizations since many Latinos do not have access to good healthcare.

HISPANIC PR WIRE

Hispanic PR Wire, Inc. (HPRW) is a Miami-based news distribution service reaching U.S. Hispanic media, organizations and opinion leaders nationwide. HPRW features a complete menu of Hispanic media circuits that includes the options of national, state and U.S.-based Pan Regional Latin America distributions. In addition, Hispanic PR Wire offers specialized distribution targeting Latino organizations as well as Hispanic elected officials and opinion leaders.

On their Web site, www.hispanicprwire.com, go to “Top Latino Links” to link to popular media outlets all over the United States. HPRW offers a free monthly newsletter via email, the Hispanic PR Monitor. Sign up is available on their Web site or, send an email with your full contact information to hispanicprmonitor@yahoo.com.

LOCAL FARMER’S MARKET

Farmer’s markets tend to be popular with many Latinos, especially recent immigrants, because fresh vegetables are very important to them and families always cook and eat at home.

Hospice Caring Project found that the local farmer’s market has a booth paid for by the County Health and Human Services that signs up local organizations to provide information. At their booth, Hospice Caring Project displays a photo board they created that illustrates the hospice circle of care with photos of a local family as well as the Latino staff of HCP. Often the HCP booth has as many as 40 direct contacts each time they attend the farmer’s market, giving staff the opportunity to answer people’s questions and distribute written materials.

PHARMACIES

Pharmacies and drugstores are a good source of health information for many people and many Latinos rely upon their services. Speak with your local pharmacy to see if they would be willing to have Spanish-language materials available on end-of-life issues to distribute.

HEALTH CLINICS

Local health clinics can be another excellent way of reaching the Latino population. Find out which clinics in your area serve the Latino community and ask to distribute Spanish-language information or make a display for their patients.

FUNERAL DIRECTORS

In the Latino focus groups conducted for Caring Connections, it was revealed that many younger Latinos make funeral arrangements in advance. Talk to local funeral directors in your area about their experience with the Latino community and see if they have done outreach to the Latino community. You may be able to partner with them to provide other end-of-life information.

For more consumer and outreach resources, see Section VII and visit www.caringinfo.org (under “Community”).



VI. Key Terms for Latino Outreach

BICULTURAL

A person who is bicultural is part of two distinct cultures, such as Mexican and American cultures. A bilingual/ bicultural Latino staff person will be able to relate more effectively to Latino families while doing outreach than someone who is just bilingual. Bicultural staff are much more adept at building trust with Latino communities than people who are solely bilingual.

BILINGUAL

A person who is bilingual is able to comfortably speak two languages, with equal or near equal fluency.

CURANDERISMO

Curaderismo is a form of folk healing which includes various techniques such as prayer, herbal medicine, healing rituals, spiritualism, massage, and psychic healing. It is a system of beliefs that is common throughout Latin America. Like other forms of alternative medicine, there are reports that these practices can improve symptoms, alleviate pain, and relieve stress. Hospice patients may desire to have curanderismo included in their care. Some curaderismo practices are well known by lay people and are done at home, but sometimes the advice or practice of a specially trained healer, a curandero/curandera, is sought.

DAY OF THE DEAD (DÍA DE LOS MUERTOS)

The Day of the Dead is an important Mexican holiday and social ritual that recognizes the cycle of life and death. This is a festival that has roots in Aztec culture yet it has Christian overtones. Each year on November 1st and 2nd, families welcome the dead back into their homes and visit the graves of their loved ones. In general, people from urban areas in Mexico are not as likely to celebrate this holiday, but it retains great importance in rural communities. The traditions surrounding the Day of the Dead may serve as an avenue for discussing end-of-life issues.

FAMILISMO (FAMILY)

Latinos place a great deal of importance on the family as the primary source of support and information. Help and advice are usually sought from the family, and important decisions are made as a group. Medical conditions and treatment are considered a family matter.

FATALISMO (FATALISM)

Traditionally, many Latinos view an illness as either “natural” (caused by God’s will or fate) or “unnatural” (caused by evil done to one by another.) In either case, a person feels that control over the illness has an external influence, and is out of his or her hands. This concept of illness has led to a fatalistic view of life and death—resulting in a person feeling that they have little to do with the success or failure of an illness. It is suspected that belief in fatalism may be in part a reason that Latinos have higher rates of advanced disease at the time of diagnosis.

HISPANIC

While “Hispanic” is a widely accepted term and often used interchangeably with “Latino,” “Hispanic” accurately refers only to people from Spanish-speaking countries. “Hispanic” is the term currently used by the US government to define citizens of any race whose family is originally from a Spanish-speaking nation. In contrast, in Latin America, the term “Hispano” (Hispanic) often refers only to people who trace their ancestry to Spain, and does not include those of indigenous or African heritage. Because of these complexities, “Latino” (defined below) generally seems to be the more flexible and accurate term. Listen to the people in your own community and refer to their group with a term that people feel is accurate and respectful.

HOSPICIO

While “hospicio” has been adopted by the hospice movement in many Spanish-speaking countries as well as by US hospices doing outreach in Latino communities, it is important to note that the term “hospicio” can have negative connotations for Latinos. People unfamiliar with the concept of hospice care may assume that “hospicio” is a bad place that is of no interest to them.

Throughout Latin America, the term “hospicio” has historically been associated with institutions for the mentally ill, the mentally retarded, and the poor or homeless. A well known mental hospital in Ecuador, “Hospital Psiquiátrico San Lázaro,” is known locally as “el Hospicio.” In Mexico, the term “hospicio para niños” was traditionally the term for an orphanage while “hospicio de pobres” (literally, hospice of poor men) was the term for the poor house.

Some hospices in the United States have chosen to use the English word “hospice” in Spanish language documents to distinguish it from the negative history of “hospicio.”

LATINO

This term is used to describe anyone from a Latin American country, whether the person speaks Spanish, Portuguese, or an indigenous language. The term Latino is more accurate than the term “Hispanic” which

refers only to people who speak Spanish. While both of these terms are widely accepted, many Latinos are uncomfortable being treated as one large group, since Latin America is a continent with many nations and varied cultural traditions.

Therefore, while it is useful to use this term to refer to a large subset of people in the United States, it is important to listen to the people in your own community and refer to their group with a term that people feel is accurate and respectful.

EL NOVENARIO/ LA NOVENA

This term is a spiritual mourning ritual that traditionally lasts nine days. Traditionally, in Latin American countries the body of the deceased was held in the home for nine days and family members prayed around it. Today, it is still common for the body to be held at home for at least twenty-four hours so that the family can pray and mourn. This practice is still important to Latinos in the United States, especially in immigrant communities. After the body is removed, the bereaved family attends mass and prays for nine days following the death of the loved one. When serving Latino hospice patients, it is important to understand what the families' expectations and needs will be directly following the death of the patient.¹

TRANSCREATE

The concept of “transcreation” is that documents should not just be translated word for word, but must be translated to ensure that they make sense both literally and culturally. Misunderstandings can often occur if materials are not translated in a culturally appropriate way. Latino culture is not monolithic—Mexican, Cuban, and Guatemalan people all have different dialects and expressions, and therefore, it is important to be familiar with your local Latino community when translating materials.

TRANSLATE

Translation of documents often means translating something word for word. Without someone who is bicultural doing the translation, it is common for literal translations to be confusing or wrong for the target audience.

EL VELORIO

This refers to the all night vigil following the death of a loved one. It is common for families to eat and drink with each other during this ritual, but the tone is still somber, one of mourning. In Latin American urban areas, el velorio may be conducted at a funeral home, but in the United States, it usually has to be done at home.²

¹Falcon and C. Yoder Falcon: *Salsa: A Taste of Hispanic Culture*, Westport, CT: Prager, 1998.

²Ibid.

VII. Resources

CARING CONNECTIONS HELPLINES

HelpLine: 800.658.8898

Multilingual HelpLine: 877.658.8896

Trained HelpLine staff are available to help people find information including:

- ◆ Locating a hospice, palliative care program, or other end-of-life care organization
- ◆ Free state-specific advance directives
- ◆ Brochures
- ◆ Information about state and community end-of-life coalitions
- ◆ Identifying local, state and national resources

CARING CONNECTIONS – BROCHURES AVAILABLE IN SPANISH

Caring Connections has educational brochures on a variety of end-of-life care topics available in Spanish to view at www.caringinfo.org or purchase at www.nhpco.org/marketplace. See list of topics below.

Bilingual End-of-Life Care Topics in Spanish/English

- ◆ Mis deseos a la atención de mi Salud: Medicas o Directivas Anticipadas – *Advance Directives: My Wishes for Medical Attention* in Spanish/English
- ◆ Cuidado Paliativo o Cuidado de Hospice – *Hospice and Palliative Care* in Spanish/English
- ◆ Apoyo para el cuidador – *How to Support Someone Caring for Another* in Spanish/English
- ◆ Las etapas en los finales de la vida – *Phases at the End of Life* in Spanish/English
- ◆ Aflicción por una pérdida – *Grief and Loss* in Spanish/English

Bilingual Pediatric Topics in Spanish/English

- ◆ Cuando Su Hijo Tiene Dolor – *When Your Child is in Pain* in Spanish/English
- ◆ Hablando Co Su Hijo Sobre Su Enfermedad – *Talking With Your Child About His or Her Illness* in Spanish/English
- ◆ Hablando Con el Medico Sobre Su Hijo: Cuando Su Nino Tiene Una Enfermedad Seria – *Talking to Your Child's Doctor: When Your Child Has a Serious Illness* in Spanish/English
- ◆ Cuando Muere un Nino: Un Guia Para Familia y Amigos – *When a Child Dies: A Guide for Family and Friends* in Spanish/English
- ◆ Como Ayudar a los Ninos a Afrontar la Muerte de un ser Querido – *Helping Children Cope with the Death of a Loved One* in Spanish





QUALITY OF LIFE PUBLISHING CO. – PHOTONOVELA

Quality of Life Publishing Co. provides a 12 page photonovela called *A Hospice Caring Story* that summarizes hospice services and staff available for end-of-life care. The story, using black and white photos, is translated in both English and Spanish languages. For view the entire booklet online or to purchase, visit www.qolpublishing.com (or call 1.877.513.0099).

PARTNERSHIP FOR PARENTS

www.partnershipforparents.org
www.padrescompadres.org

An online support program, available in English and Spanish, for parents caring for children diagnosed with a serious illness that was developed by the Children's Hospice & Palliative Care Coalition.



VIII. Acknowledgements

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IX: Appendix

Click on links below to view and download the documents. All documents may be accessed at

www.caringinfo.org/community

then clicking on “Diversity Outreach”.

Community PowerPoint presentations — with speaker notes (*Spanish and English versions*)

- A. *Making End-of-Life Decisions (English ppt)*
- B. *Making End-of-Life Decision (Spanish ppt)*
- C. *Hospice Can Help You and Your Family (English ppt)*
- D. *Hospice Can Help You and Your Family (Spanish ppt)*



NOTES


Caring Connections
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