

Empodérate: Empower Yourself



Health Empowerment Workshop

English Version!

Familias en Acción

Our Mission

Familias en Acción was founded in 1998 to promote and ensure better and healthier lifestyles to reduce chronic diseases like cancer, diabetes, obesity and other conditions that affect our communities. Our mission is to promote holistic family well-being for Latinos through community engagement, education, research and advocacy for social change.

Mission Delivery

Our priorities include chronic disease prevention and education, cancer survivorship, community leadership development, elimination of health disparities and community based participatory research.

The patients served by Familias en Acción are:

- Insured and uninsured
- Residents of Oregon and SW Washington
- End Stage Renal Disease patients, ~40% of clients under the age of 40

Patient Navigator Program

- Over 300 cancer survivors and their families served per year
- 5,000 individuals receive chronic disease prevention and education
- 500 uninsured individuals receive cancer screenings
- Access to Primary Care services

Health Training for Health Professionals

- Annual Latino Health Equity Conference
- Culturally competent clinical care

Community Education

- eSaludToday online health magazine
- Chronic disease self-management program
- Community chronic disease prevention and education

Our Patient Navigators partner with health care personnel to provide:

- Chronic disease education
- Patient and family support for chronic disease self-management
- Reducing language and cultural barriers to clinical care
- Psychosocial support for survivors and their families
- Palliative care for patients and their families including psychosocial and spiritual support
- Referral to community social service services
- Nutrition and exercise program
- Monthly support group

Patient Navigators serve an important role to:

- Reduce health care costs
- Increase appropriate utilization of and access to health care services
- Reduce risk of avoidable health complications
- Improve health status
- Increase health literacy

For more information please call:

503-201-9865

www.familiasenaccion.org

Empower Yourself Health Empowerment Workshop

Palliative Care
For our Latino Families

Developed by:
 **Familias en Acción**

Funded by:
Cambia Health Foundation Sojourn Program

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Empoderate: Health Empowerment Workshop

What is *Empoderate*?

***Empoderate* is a tool to reach into our Latino community to empower individuals and decrease health disparities.**

This program introduces participants to concepts around patient centered care and encourages them to take an active, decision-making role in managing their chronic illness. Participants will be aware of palliative care and be more ready to access it or hold end of life discussions when the time comes.

Patients with chronic illness and their family members are welcomed to a two hour session:

Empoderate sessions are warm, non-judgmental and lively!

New ideas are brought to neighborhoods where people gather and are comfortable.

Information is provided in Spanish and does not require high literacy skills.

Activities engage participants and reinforce the messages.

Incorporating time to plan "Action Steps" personalizes the learning and moves people toward behavior change.

Empoderate responds to questions and information gathered in focus groups and from pilot sessions. Written in Spanish and translated into English, it reflects the culture of facilitators and participants.

***Empoderate* follows a train the trainer model--it is fun and easy to facilitate.**

The manual is easy to follow and gives clear instructions to facilitators--but still allows for personalizing to fit the facilitator's style and the needs of the group. Activities are simple and require very little preparation or supplies. *Empoderate* facilitators are excited by the enthusiasm of the group and moved by the sense of power people feel during the session.



What are people saying?

Participants--"Now I know what I can do to support my husband with his illness" "I don't have to be confused about how to get the care that our family needs." "I will be ready next time I go to the doctor."

Trainers--"This is so easy--it is all laid out for me." "It is so gratifying to help people gain understanding that encourages them to take charge of their health."

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Trainer's Guide:



Introduction

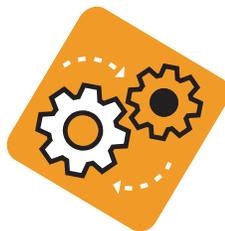
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Empoderate brings new ideas to the neighborhoods where people already gather and feel comfortable. It responds to attitudes and information gathered in focus groups and from pilot sessions. Written in Spanish and translated into English, it reflects the culture of facilitators and participants.

The manual is easy to follow and gives clear instructions to facilitators--but still allows for personalizing to fit the facilitator's style and the needs of the group. Activities are simple and require very little preparation or supplies. *Empoderate* facilitators are excited by the enthusiasm of the group and moved by the sense of power people feel during the session.



What is Palliative Care?

Palliative Care is a relatively new kind of specialized medical care that is available for people diagnosed with complex medical conditions. However, most people are not aware of it and it is often misunderstood.

"Palliativo" in Spanish is often changed to "hospicio" which has negative meanings such as hospital, orphanage or poor house.

Defining Palliative Care

Palliative Care is a medical specialty but **it is also a philosophy or attitude about patients and life.**

Palliative Care offers relief from suffering to patients with serious and complex illness. It addresses the "whole person" and the family (physically, emotionally, and spiritually). It does not replace other medical care but works together with it.

This means that the patient can experience the best possible quality of life while dealing with the illness. And the family gets the support they need in order to continue to provide care to the patient.

Understanding Palliative Care

Who can get Palliative Care:

- ◆ People who have a serious illness-- with any kind of diagnosis
- ◆ People at any stage of the illness
- ◆ People of any age
- ◆ The patient and the family

What Palliative Care does:

- ◆ Can improve the quality of life and help the patient and family live better with the disease
- ◆ Looks at the "whole" person including emotional and spiritual sides
- ◆ Offers relief from symptoms and pain
- ◆ Can help the patient tolerate medical treatments
- ◆ Offers support from stress
- ◆ Helps the patient and family members understand the disease
- ◆ Helps the patient and family take an active part in choosing treatment options and goals
- ◆ Helps the patient and family navigate the medical system
- ◆ Can work alongside other curative treatments

Who provides Palliative Care:

- ◆ This is a team working together--doctors, nurses, social workers, and other specialists.
- ◆ They work with your other doctors and do not replace them.
- ◆ Religious leaders or supports may be included.
- ◆ Patient navigators are an important part of the team.
- ◆ Depending on what is available locally, this care may be offered through a hospital or through outpatient services.

For the patient and family

The team becomes *your* team. They are available to spend time with you answering questions, getting all of your providers to communicate together, helping you understand your illness.

What Palliative Care is NOT...

It does not mean you are "giving up" or that you are dying. In fact, getting support can give you more strength to fight your disease.

It does not mean the family is giving up or asking others to step in to offer care. In fact, getting support can help families give better care.

How to get Palliative Care:

Palliative Care *may be offered to you* by a doctor or hospital. You may *need* to ask and say : "I have heard there is something called Palliative Care. I would like to receive this."

If it is not available where you live, because you asked, your doctor will know that getting this kind of support is important to you and your family. He or she can help you find it in other ways.

For the patient navigator or promotor

Investigate what is available in your area:

- ◆ Use the term "Palliative Care" when you ask.
- ◆ It is most commonly offered through a hospital but there is more being offered to outpatients.
- ◆ Hospital social workers might be aware of similar services even if they are not defined as palliative care.
- ◆ Be ready with the details before you talk with families.

Give clear explanations to patients and families:

- ◆ Remember that this is a new concept.
- ◆ Explain what Palliative Care is and what it is not.
- ◆ Be clear about the difference between Palliative Care, hospice, end of life care.
- ◆ Be prepared for families to refuse what they consider help from outsiders.
- ◆ Use examples of other families that have received palliative care.

Emphasize how well Palliative Care fits Latino values:

- ◆ Family members are included in decision-making and communication.
- ◆ Patients and families are treated with respect and educated about the illness.
- ◆ Spiritual wishes are included.
- ◆ Emotional stress is recognized.

You are an important part of the Palliative Care team:

For teams not accustomed to working with patient navigators, this is an opportunity for you to show the value of navigator as liaison and cultural representative.



“This guide is a toolkit for you to get empowered while empowering others.

Remember that knowledge is power. Participants of these workshops will thank you for ever for teaching them to strive for better quality of life.

Education and knowledge are the best gifts we can ever give others.

Go and empower them!

Empodéralos,

Gracias.

Olga Gerberg

Patient Navigator Program Director

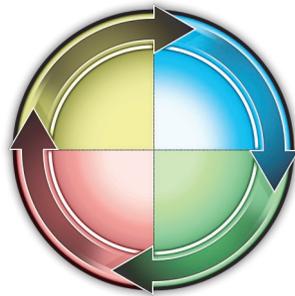
Why is Empoderate Necessary?

Even though Palliative Care fits well with Latino cultural values, it is very underused by Latinos.

The use of Palliative Care will be one way to decrease health disparities and improve health outcomes.

Increasing the use of Palliative Care by Latinos will take forward thinking on the part of all involved:

- ◆ Medical providers,
- ◆ Patient navigators and promotores,
- ◆ And the Latino community members themselves.



Patient centered care has been identified as a goal for medical care.

- ◆ Patients need to understand their medical conditions.
- ◆ Patients need to take an active role and be active decision makers.

But some Latinos are not ready to be active partners in their medical care because they may be:

- ◆ New to this country
- ◆ Not fluent reading or speaking English
- ◆ Confused by the medical system
- ◆ Overwhelmed by the effect of their illness
- ◆ Experiencing social barriers of poverty

Why is Empoderate Effective?

Empoderate starts at the beginning.

1. You will prepare patients and their families to eventually access Palliative Care by helping them:

- ◆ understand the chronic nature of their illness
- ◆ understand their role in accessing medical care
- ◆ understand how partnering with their medical providers can improve their health outcomes.

2. Then you teach them practical skills to accomplish those goals.

The style of the session itself models participation in learning.

3. Empowered with those skills they will be able to ask for and use Palliative Care when the time is right.

The medical provider is the expert on disease, but the patient is the expert on how the illness is affecting him/herself

Why are YOU the Best Facilitator?

- ◆ You can be the link between the two worlds.
- ◆ You understand the challenges experienced by participants.
- ◆ And you can offer new information in culturally sensitive ways.

Patient navigators and promotores are being more recognized as a valuable member of the care team.

Medical providers are learning to see them as important connections to the Latino community and as their link to providing culturally sensitive medical care.

Goals and Objectives

The goals of *Empoderate* are to:

- Raise health literacy
- Encourage full use of medical care
- Lead to a beginning understanding of palliative care and be more ready to access it when the time comes.

Specifically, participants will:

- Recognize the importance of balanced care for chronic illness-physical, emotional, mental, spiritual
- Know how the definition of "chronic disease" fits their own health situation
- Know that palliative care is care that supports the whole patient and family as chronic illness progresses.
- Understand the patient's role in the American healthcare system
- Understand ways to take an active role in their health care, such as: prepare for medical encounters, formulate questions about their treatment, and keep records

Materials Needed:

- ◆ Printouts from masters provided
- ◆ White board or poster paper
- ◆ Markers and pens
- ◆ CD player optional



Design of the Manual

Following the "warm up" and introductions, there are 5 sections and a conclusion.

Each section includes:

Learning objectives

Preparation or materials needed

List of activities

Note to facilitator

Talking points

Additional tips for the facilitator are called out occasionally

Please consider this manual a handbook and not a prescription. As you become knowledgeable about the objectives and comfortable with the subject matter, you can make changes to fit your style. You will find that the needs and personality of each group are different and you will want to adjust the amount of time spent on topics, the style of activities, etc.

Masters to print

Master copies of materials needed for activities or handouts for participants are found at the back of the manual:

Handouts for participants

Diagram: "Wheel of Life"

Tool "Pathways to my Health"

Program Evaluation Tools

Examples of pre and post questionnaires

Resources

References and resources for your use



Planning an *Empoderate* Session

Define Your Audience

Empoderate is designed for Spanish speaking people who are dealing with chronic illness. Because illness affects the entire family, encourage family members to come, too.

A new way of thinking about illness and disease:

A disease is the change that happens in a person's body. The word illness is about how a person responds to the disease. People in your session will be "people dealing with chronic illness" because you will be addressing the "whole" person.

Use "People First" language: A person may be diagnosed as being "a diabetic." But to acknowledge the whole person we may say "a person with diabetes."

Recruiting Participants

Word of mouth is the best publicity! Contact church leaders, business owners, health centers...anywhere people already gather or places where they receive services.

Use the class descriptions and graphics found in the Publicity Aids section of this manual.

Remember to use social media--Facebook, Twitter, Instagram--to target young people in particular. Young people are sometimes the window into a family.

Offer the session for free. Provide food, if you can!

Logistics

Meeting room: use the same contacts to find meeting space. The room needs to be accessible to all, comfortable, and big enough to move around during activities. A white board, or way to hang poster or flip-chart paper, is helpful.

Childcare: if possible, offer childcare.

Signs: since you will be using every second of your time, make it easy for people to find your room and settle in.

Co-leader: Although one person can lead the sessions, it can be helpful to have an assistant to help pass out materials, greet participants, handle logistic issues that may arise.

Using Your Manual

Review the Manual

Read through the entire session to understand what you will accomplish and get a feeling for the flow.

Prepare materials

Gather any supplies for your presentation (flip chart, markers, Wheel of Life) and for Activities. Make copies of written handouts. Prepare a sign in sheet. It can sometimes be challenging to get a lively group's attention after an Activity. Consider bringing a noisemaker and explain before you begin how you will use it.

Practice

Going through one section at a time, read through the **Talking Points** until you are comfortable. If you use your own words, ask yourself if you are still accomplishing the objectives.

Practice facilitating the **Activities** until you can lead them smoothly.

Plan ahead for any adjustments you might need to make in order to include people who are experiencing physical or emotional discomfort.

Give thought to how you will end the session

Asking questions noted in Program Evaluation Tools can be a way to "cement" the learning and give you valuable information. Your goal is to end the session with participants feeling empowered in new ways. The ending visualization using the Wheel of Life can be used after the questions to bring participants back to a point of balance in their own lives.

Ending the Workshop

Asking questions noted in Program Evaluation Tools can be a way to "cement" the learning and give you valuable information. Your goal is to end the session with participants feeling empowered in new ways. The ending visualization using the Wheel of Life can be used after the questions to bring participants back to a point of balance in their own lives.



Introduction and Ice Breaker

Note to facilitator:

- Introduce yourself, your organizations and sponsors, and your volunteers.
- Describe the goals for this workshop (see previous section)
- Lead the group through the exercise and then discuss.
- Point out the strength and creativity people use to fight obstacles.
- Focus on personal power and use of supportive people.

Activity:

Going Fishing



Guiding Script for Facilitator:

“We are going to do an exercise to help us know ourselves. Get comfortable in your chair because we are going to go on a little trip in our minds. Look around you and then close your eyes whenever you are ready. Take a deep breath and exhale. Now imagine we are leaving this room and we are going fishing. You are carrying your fishing rod and walking down the path. You notice a log in the middle of the path, so you need to decide how you can get passed it. Then you encounter a creek that has overflowed and it’s covering part of the path and you need to figure out how to cross it, Can you do it alone? Do you need help from someone else? Who is nearby to help? Finally, you make it to your destination and you can enjoy a great day of fishing.”

How did you feel with your eyes closed? How did you feel when you saw the obstacles? How did you react to these obstacles? Life is full of obstacles and challenges we must face. There are many ways to approach them but it is up to each one of us to make the decisions for ourselves.

Section 1

Finding Strength as a Latino to Balance our Life

Goals:

- Identify the different aspects that make up a person: physical, emotional, mental and spiritual.
- Start conversations about how to achieve a balanced life.
- Learn how to use the “*Wheel of Life*” model during a chronic illness.

Materials:

- Flip chart or blackboard and markers
- “Wheel of Life”

Activities:

- Getting to know each other
- Balance in the “Wheel of Life”

Note to Facilitator:

Place a large “Wheel of Life” diagram in a visible place since this will be your frame of reference for the entire workshop.

Start by asking participants who feel comfortable to share stories about difficult situations they have faced in their lives and how they have overcome them. After you ask the question, give people time to think of their situation before moving ahead

ALTERNATE: If you sense the group is not ready yet to be so personal, or if you are concerned about time, give people a few moments with the person next to them to vent the personal issue/event--then they will be ready to share the other ideas in the next step more readily and it will take less time.

If it is not already there, lead the discussion toward experiences around their health issues.

When you introduce the “Wheel of Life,” write the titles in the sections. As you or the participants talk, point to the section in the Wheel.

Guiding Script for Facilitator:

“Let's talk now about some real life situations. Think of a time in your life when you faced something that had the power to change your life. Got something in mind? How did you deal with it? What qualities/skills/strengths did you bring to the situation?”

This circle represents a “Wheel of Life”. Each of us is made up of these four parts: Physical, Mental, Emotional, and Spiritual. Ideally, the wheel is round and everything rolls along smoothly. But what happens to a wheel when one part is too full? Or when one part is too flat or empty?”

Science has now found that the four parts affect each other. Our emotions can affect our physical health. For example, stress (Emotional) may cause or certainly make illness worse. Our thoughts (Mental) can affect our physical and emotional health. Spending time with fear, anxiety, worry, and guilt can prevent us from experiencing optimal health. Our goal is to have a balanced life.

Sometimes during times of stress or illness, the balance gets thrown off. When we first hear the diagnosis from the doctor, each of us reacts differently. Some people fall into depression (Emotional) and let negative emotions keep them stuck. Other people go right to their Intellectual part and they want to learn everything they can about their condition. Others cannot help but focus on their Physical part because they are experiencing symptoms like nausea, fatigue, pain. Others go to their Physical part and begin making lifestyle changes like diet or exercise in order to keep the body as healthy as possible.

Latino Health Fact

Nearly two-thirds (63%) of Hispanics report receiving some health information from family or friends, and about one in three (31%) credit community groups and churches as sources.

Source: National Council of La Raza (NCLR). 2009: *Profiles of Latino Health*.

Section 2

Defining what is a Chronic Disease

Goals:

- Define the terms and note differences between chronic disease and curable disease.
- Describe how a chronic disease can affect our whole self.
- Introduce the concept of Palliative Care.

Materials:

- ◆ *Senderos hacia mi Salud* booklet
- ◆ Definitions of chronic disease and treatable disease (optional)

Activities:

- ◆ Complicated Diagnosis

Note to Facilitator:

This activity is meant to be fast and confusing to demonstrate how the health system and chronic illnesses can be very confusing.

Ask participants to stand up, or raise their hand, every time they hear you shout out a word that relates to their lives and/or diagnosis. Examples are: high blood pressure, cancer, diabetes, diet, stroke, exercise, treatment, surgery, biopsy etc.

Start a conversation after the activity about how difficult and confusing doctors' appointments can be. Continue to point to sections on the *Wheel of Life* as appropriate.

Allow people to debrief about the activity and talk about their experiences.

End with a brief definition of Palliative Care. *Simply, it means offering medical care to the "whole person." Not just looking at the disease--the Physical part-- (point to Physical) but looking at the other parts, too. What can be done to ease sadness? How can we bring prayer into a hospital room? How can the patient help make decisions about treatment? We must play an important role in our own health. It will be up to you or your family to ask for Palliative Care.*

Guiding Script for Facilitator:

Let's talk more now about the Physical side. Many of you, or your family members, are facing what doctors call a Chronic Disease or a medical condition. Some of you just met with the doctor; others have been dealing with your illness for a while now.

To get a feel for what everyone in the group is dealing with, I want you to do an exercise with me. Exercise is a good word because you may be getting exercise while we do it! I am going to name some diseases or words that relate to illness. Stand up, if you are able, or raise your hand when I say something that your doctor has told you. Ready?

[Examples: high blood pressure, cancer, diabetes, diet, stroke, exercise, treatment, surgery, biopsy etc]

No wonder it is confusing and hard to understand our medical conditions! It is common for your head to be spinning from all the information. And when your heart is worried, it is hard to hear what the doctors say.

[point to Emotional and Mental on Wheel of Life]

Let's take a moment to get rid of some of the confusion! Understanding the kind of condition you have will help you know what to expect.

*What is a chronic disease and how is it different from a curable disease? When a medical condition is **curable** the symptoms usually come on quickly, can be pretty severe, but do not last long. The patient may or may not get medical care. Examples might be: kidney stones, colds, flu, ear infections.*



When a medical condition is **chronic** the symptoms come on slowly, usually progress slowly, but continue to last and will get worse. Most chronic conditions need medical care, and lifestyle changes, that can help slow the progress. But there is no cure. Some examples of chronic diseases are: arthritis, diabetes, cancer, heart disease, stroke, kidney disease.

For a chronic disease the "cure" is not the goal--until we have medical advances that could bring a cure. Instead, the goal is to treat and manage the disease.

When we or a family member are diagnosed with a chronic disease we should follow medical recommendations--medicine, therapies, and treatments-- that can slow the progression of the disease and even control the symptoms. It is also important to make lifestyle changes--diet, exercise, reduce stress, and get enough sleep--that can slow progression, lessen the discomfort, and improve the quality of life.

The goal is to keep you or your family member as healthy as possible for as long as possible.

I want to introduce a new medical term to you. That is: Palliative Care (write the word on the board). It is also new to the medical community. But we may be hearing it more and more, so I want you to be aware of it. Simply, it means offering medical care to the "whole person." Not just looking at the disease--the Physical part--(point to Physical) but looking at the other parts, too. What can be done to ease sadness (point to Emotional)? How can we bring prayer into a hospital room (point to Spiritual)? How can the patient help make decisions about treatment (point to Mental)? We must play an important role in our own health. It will be up to you or your family to ask for Palliative Care.



Section 3

In Charge of your Own Health

Goals:

- Explain the importance of managing our own health, of navigating and participating in the health system.
- Discuss the importance of asking our doctors questions about our diagnosis and treatment, and the importance of knowing how to interact with health providers.

Materials:

- White paper plates -one for each participant, pens or markers
- Blackboard or flipchart with Positive Negative Attitudes graphics drawn on it.

Activities:

- In Charge of Your Destiny
- Positive and Negative Attitudes

Note to Facilitator:

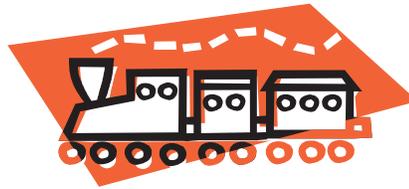
Ask for as many participants as feel comfortable moving around the room to participate in this activity. Line them up with each holding onto the waist or shoulders of the person in front of them. The facilitator becomes the front of the line and leads them around the room as if they were a train --move in different directions and move fast and slow. Get people laughing or falling off the train so they feel somewhat out of control!

Once the “train” stops give each participant a paper plate to use as a car steering wheel and ask them to “drive” back to their seats.

As the volunteers sit down, pass a paper plate to the rest of the participants. When you ask them to write on their plate, write the word "Driver" on the board.

Place the poster of Positive and Negative Attitudes in a visible place to begin the next topic.

As you talk about negative attitudes hold a paper steering wheel and turn yourself in circles by always turning left. As you summarize the discussion, hold your paper wheel and drive straight ahead enjoying the drive.



Guiding Script for Facilitator:

If you want to live in the best possible health you will need support from the American medical system. Let's take another look at the medical system in America. If you are comfortable walking, please come near me for the next activity. Or you can sit and watch. Don't worry--all you have to do is be ready to go on a train ride!

Line up making one long line. Put your hands on the waist or shoulders of the person in front of you. I am the Conductor of this train! Follow me!

[When the train stops] The advantage of a train ride is that you go pretty fast. But we all had to go to the same destination. I was in charge of you! Instead of a train, now let's go on a car ride. Here is your steering wheel--drive yourself back to your seats.

The advantage of driving a car is that YOU are in charge! Sure, there are rules of the road to follow but YOU get to choose where you go, how fast, what road to take.

This is a way to understand the US medical system. To navigate through it, you must become the driver of the car. You should be a partner WITH your doctor: ask questions, ask for what you need, be a part of treatment decisions, follow through with treatment plans.

*On your paper "steering wheel" write a note to yourself. Write your name and the word "Driver" in big letters. When you get home, put it someplace where you will see it every day as a reminder. . **I am the driver in charge of driving the road to my health.***

Section 4

Getting the Most from Your Doctor

Goals:

- Develop skills to manage and navigate the healthcare system
- Learn steps to take to be ready for a doctor's appointment
- Learn how to use the "Pathways to my Health" tool (Senderos booklet)

Materials:

- "Pathways to my Health" tool (Senderos booklet)
- Scripts for role play activity
- Pens and paper

Activities:

- Role play of a visit to the doctor's office

Note for Facilitator:

Pose the question that everyone can relate to: planning a family party. Let them call out ideas--add your own, if needed. Examples: check the cupboards, make a list, call to be sure your favorite uncle will be there, ask your sister to make her famous dish.

Have examples ready if you need to help them list what they might need to plan a doctor's appointment. You don't need to give them all now because you will cover them when you go through the "Pathways to my Health" tool. Examples: Identification, Insurance card, List of medications, List of questions, Paper and pen to write notes or dates of appointments.

Hand out the "Pathways to my Health" tool and go over all the sections and how they can be used. Review the type of information that participants can put in it and how having it will help in future interactions with health providers.

Begin the role play activity by asking for two volunteers.

After Scene #1 stop and discuss.

After Scene #2 lead a discussion about the differences between the two scenes. Point out how much more powerful the patient feels!

Guiding Script for Facilitator:

Planning for a doctor's appointment is like planning for a family party. What do you need to do to plan for a party?

Planning a party can be pretty stressful but not as stressful as going to the doctor when you don't feel good...or when you are worried.

Going to the doctor takes planning, too. What are some things you need to do and bring for a doctor's appointment? What documents? What information?

Let's get very practical for a moment. There are things you can do to make your appointments go more smoothly. (pass out the "Pathways to my Health") This is a tool to help you stay organized--to keep your medical information in one place.

There are places to write your address, the list of medications, and more. If it is complete, you may be able to hand it to the doctor rather than having to explain the information every time you go to the doctor. We will be using it as we continue today. (Go through each section with the participants)

It is very important to think of questions before you go--write them down as you think of them and bring the list along. It is human nature, especially when you are stressed and not feeling well, to forget everything you planned to say!

Doctors EXPECT you to ask--it is your job as the patient and it is their job to listen. Tell the doctor you have a list of questions and will need him or her to spend a bit more time with you. You deserve it!!!!

To prepare this class we interviewed lots of doctors and they all said the same thing: We WANT our patients to ask questions. We want to be sure that they understand...and that they agree with the treatment decisions.

Let's act out some typical scenes at the doctor's office. I need 2 volunteers--one to be the patient and one to be the a relative.

Activities:

Role Playing a doctor's appointment

Note to Facilitator:

Ask for two volunteers to participate in acting different roles. The facilitator will be acting as the doctor. Distribute the scripts and give the participants some time to read it.





Scene #1:

Doctor: this patient has had lots of tests and is coming back to your office now to get the results. You must tell him: "You have diabetes, and now you need to start monitoring your blood sugar, take insulin, and stop eating sweets."

Patient: You listen politely and nod your head. You probably stopped listening right after you heard the word "diabetes" because your mother had it and it was pretty bad for her. At the end of the appointment you feel confused and cannot communicate with your relative.

Relative: You have never known anyone with diabetes. You have no idea what the doctor is talking about but you assume that the patient knows because s/he has had family experience. When you leave the office you ask them: "Did you understand what the doctor was telling you? Now you know what we are supposed to do and how our lives need to be adjusted?" You get mad at your relative for not being able to tell you what this will mean to your lives.

Note to Facilitator:

Lead the discussion: *How did you feel about this appointment? What felt familiar to you? How do you think the patient was feeling when he/she arrived? How did he or she feel when they left? How did the relative feel? How did the doctor feel?*





Scene #2:

Doctor: the doctor gives the results to the patient and tells him/her “you have diabetes and now you need to make some changes in your life-style”

Patient: He/she listens and then looks at the “Pathways to my Health” tool and reads the frequently asked questions and asks the doctor: “What is diabetes? What changes do I need to make? Is this a chronic disease? What do I need to do to manage the disease? Can it be cured? What do I need to do to manage the disease?”

Relative: He/she takes notes about what the doctor is telling them and reminds the patient to ask about treatment, medicines, diet etc.

Note to Facilitator:

Lead the discussion:

What is different about the two scenes? How did the patient feel at the end of the appointment? How did the relative feel? How did the doctor feel? What other questions could they have asked?

This was a powerful patient driving his own appointment!



Section 5

Understanding our Medications

Goals:

- Explain the key features of medications to be aware of: the purpose, dosage and side effects.
- Explore how our family can be of great support when facing a chronic disease.
- Encourage participants to talk to their doctors before, during and after

Materials:

- Board or flip chart, marker
- “Pathways to my Health” tool (Senderos Booklet)

Activities:

Using the “Pathways to my Health” tool to take notes about medications

Note for Facilitator:

- Open the discussion about medications with questions. Note their ideas on the board.
- Discuss why it is important to understand all aspects of our medicines. Write the topic names on the board and then discuss each: Purpose, Dosage, How would it make me feel? How long should I take it? Refills
- Listen to any concerns and questions from participants and always try to see if the group can answer their own questions.
- Asking them to actually write in their booklet will be a step toward personalizing and using it as a tool
- Naming one supportive person is a concrete action step.
- End this section with the empowering thought: they are experts of their own bodies.



Guiding Script for Facilitator:

One of the most important things you need to understand is all about your medications. What things do you need to know about your medicine? What questions should you ask?

Each medicine is unique and very specialized so it is important to know and understand the purpose, the dosage, and the side effects of your medicines.

What is the purpose of your medicines? Do you know the dosage you are taking? Do you understand how they are making you feel?

Purpose: *What will this medicine do for me? Some medicines help us feel better. Some medicines make our disease get better. Some keep our disease from getting worse.*

Dosage: *How much do I take? How often? American drug prescriptions are written specifically for one patient. The kind and amount depends on your age, weight, condition. Do not take medicine that was not specifically given to you by the doctor. Do not give YOUR medicine to someone else--it could make them very sick. It is important to take it exactly as the doctor or pharmacist tells you.*

*How should I expect to feel? Better? Worse? **Side effects?** How long will it take to feel better? Sometimes you can tell right away that a medicine is working because you feel better. Some medicines might make you feel worse because they are powerful and doing a powerful job in your body. Many medicines for chronic disease you take to keep your condition from getting worse--you may not feel any effects. If you feel much worse call the doctor immediately. The doctor will decide if you should stop or maybe change to a different kind of medicine.*

How long should I keep taking it? Take all of the medicine you have been given. When it is gone, ask the pharmacist if there are "refills." Often it says right on the bottle or box. If so, go back to the pharmacy right away to get more so that you do not miss any doses. Ideally, plan ahead by noticing when you are starting to run out.

No one can remember all their medications! There is a place in your "Pathway to my Health" booklet to write medications. Take a moment now to think/write ONE medication that you take. Do the rest when you go home.



Activity:

Remembering our medicines. Ask participants to write down the names of all the medicine they are currently taking, and discuss how difficult it is to remember them all. Ask participants to make sure to write them down on the section of the *Senderos hacia mi Salud* booklet when they get home.

Bonus Activity:

Use the following conversational topics to enhance the sense of empowerment and active role of participants in their health care and treatments

Trust your Family

Guiding Script for Facilitator:

Even if you write everything down and feel very prepared it is so helpful to have someone with you supporting you along the way.

Who in your family supports you?

Bring an important family member with you--introduce him or her to your doctor so your doctor knows this person is important. This person can be another set of "ears" to help listen and remember; can help you navigate your way to the office, lab, etc.; can ask the questions that you might forget.

Decide: Who is the person you can take with you?



Talk to your Doctor

Guiding Script for Facilitator:

Your doctor will ask you questions. He or she cannot tell what your body is feeling! He or she cannot read your mind. He or she relies on you to tell him or her accurately how you are feeling, how much pain are you in.

This is the time to set aside your pride or embarrassment so that you get the best possible treatment.

Remember, you are partners. He or she may be the expert about medicine but you are the expert of your body and your life!



Section 6

Understanding Palliative Care

Goals:

- Emphasize the importance of Palliative Care
- Reflect about what we can do to balance our own “Wheel of Life”
- Review key points.
- Assess learning through Post Evaluation

Materials:

- “Wheel of Life”, markers
- Evaluation tool
- CD player and CD with calm and relaxing music

Activities:

Imagining our own “Wheel of Life”

Note to Facilitator:

Refer back to and point to the picture of the Wheel of Life. As you review the definition of Palliative Care write the words "Palliative Care" across the top of the Wheel of Life page.

Ask the Post Questions as a way to review key points and assess learning achieved through the session.

Play a relaxing song and walk participants through a visualization exercise to end the session.

Guiding Script for Facilitator:

Let's end our time together today with some quiet time to assess our own Wheel of Life. Get comfortable in your chair, Close your eyes....

Let's start with the Physical. How is your body feeling? Are there places that are sore or tired? Concentrate on those places and relax them.

Mental. Your head is full of new information. Check in with your forehead. Relax those muscles. Let the new information sink back into your brain with no effort at all.

Emotional. Check in with your heart. How are you feeling? Sad? Encouraged? Cared for?

Spiritual. How do you feel right now? Do you feel the strength to share what you learned today? What can you do to find that inner peace? Where can you find it?

When you are ready, open your eyes. Take your steering wheel and your tools with you when you leave. You are more ready now to drive back into your very balanced life.



Program Evaluation Tool

These tools can be used in many ways depending on the needs of your organization.

They have not been standardized and are not intended to measure concrete outcomes.

Many in the target audience may not be comfortable writing or proficient at "test taking." Therefore, the Pre and Post Questions are asked and answered verbally. The facilitator will gain subjective information that will help determine if the goals have been met and learning has occurred.

Use is optional unless required by your organization. Pre and post tests can be used together or singly.

Use the PRE-TEST:

1. to gain a sense of the participants' current level of knowledge before you begin (this may help you gear your presentation appropriately)
2. as a "warm up" to session.

Use the POST-TEST:

1. to determine whether participant awareness and knowledge has increased
2. to identify individuals who may need personal follow up.
3. as an opportunity to leave participants with correct information
4. as a closing exercise
5. to gain insight about planning future session--points in the session that were particularly effective or not effective.

How to use the tools:

Remind participants as you open with Pre Questions that you *do not expect* them to know the answers yet, but they will know more at the end of your time together.

After each of the 4 questions some of the concepts you are looking for in their comments and answers are listed. If participants do not give them, use this as another teaching opportunity and offer more information as a summary.

Pre and Post Verbal Test:

1. When you are living with a chronic illness, what is the most important thing to deal with: physical, emotional, intellectual or spiritual?

POST: all should be in balance; many Latinos value spiritual support and can ask to include it in their care

2. Doctors use the word "chronic disease." Raise your hand when you hear a disease that would be considered chronic: cancer, flu, head cold, high blood pressure, broken arm, diabetes

POST: cancer, high blood pressure, diabetes

Define--chronic disease is one that can be treated but will not get better

3. True or False: Doctors like it when you ask them questions about your illness.

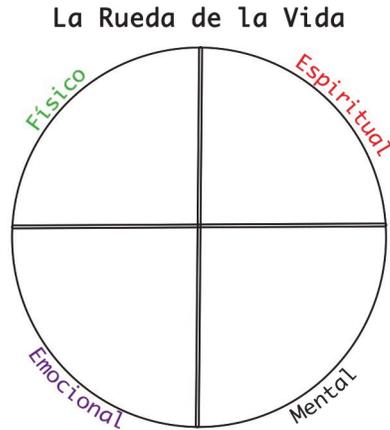
POST: Doctors appreciate you taking an interest in your own care. Asking questions is part of taking an active part in your own care.

4. True or False: Palliative care means it is time for someone else to take care of you.

POST: means support for the whole person and the family as a disease gets more difficult to manage; does not mean you are giving up and does not mean the family will be less involved in care

Masters to Print and Copy

1. Wheel of Life



2. Positive and Negative Attitudes

Positivas 	Negativas 

3. Section 2: Defining Palliative Care

Palliative Care: *Simply, it means offering medical care to the "whole person." Not just looking at the disease--the Physical part--(point to Physical) but looking at the other parts, too. What can be done to ease sadness? How can we bring prayer into a hospital room? How can the patient help make decisions about treatment? We must play an important role in our own health. It will be up to you or your family to ask for Palliative Care.*

Section 4: Getting the Most from Your Doctor

Activity: Role playing at doctor's office

Scene #1:

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Patient: You listen politely and nod your head. You probably stopped listening right after you heard the word "diabetes" because your mother had it and it was pretty bad for her. At the end of the appointment you feel confused and cannot communicate with your relative.

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Relative: He/she takes notes about what the doctor is telling them and reminds the patient to ask about treatment, medicines, diet etc.

References & Resources

American Cancer Society-

24 hour information-1-800-227-2345

Cuidados Paliativos Durante el Cáncer: Instituto Nacional de Cáncer

<http://www.cancer.gov/espanol/recursos/hojas-informativas/apoyo-recursos/cuidados-paliativos>

Cuidado Paliativo de México-

<http://www.cuidadospaliativos.org.mx/>

The Leukemia & Lymphoma Society Oregon SW Washington Idaho Montana

9320 SW Barbur Boulevard Suite 350, Portland, OR 97219,
(503) 245-9866

Livestrong Foundation Patient Navigator Services-1.855.220.7777

livestrong.org

Minnesota Network of Hospice & Palliative Care Latino/Hispanic Guide, 2010.

Multnomah County Community Capacitation Center-

<http://web.multco.us/health/community-capacitation-center>

Oregon Community Health Workers Association-

<http://www.orchwa.org>

Providence Hospice of the Gorge-

1630 Woods Ct, Hood River, OR 97031

Phone:(541) 387-6449

<http://oregon.providence.org/patients/programs/providence-hospice/Pages/default.aspx>

State of Oregon Office of Equity and Inclusion-

<http://www.oregon.gov/OHA/oei/Pages/index.aspx>

Susan G. Komen for the Cure Oregon and SW Washington-

<http://www.komenoregon.org/>



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