Hospice Use Among Hispanic/Latino Older Adults

MHP Salud Technical Assistance Call

3.17.2021

www.mhpsalud.org
El uso de Hospice entre adultos mayores hispanos

Llamada de asistencia técnica de MHP Salud
17.03.2021

www.mhpsalud.org
Who are we?

MHP Salud is a national nonprofit organization that implements and runs Community Health Worker (CHW) programs. These programs provide peer health education, increase access to health resources and bring community members closer. MHP Salud also has extensive experience offering health organizations and service providers training and technical assistance on CHW programming tailored to their specific needs.

www.mhpsalud.org
¿Quienes somos?

MHP Salud es una organización nacional sin fines de lucro que implementa y administra programas de promotores(as) de salud. Estos programas brindan educación sobre la salud entre pares, aumentan el acceso a los recursos de salud y acercan a los miembros de la comunidad. MHP Salud también tiene una amplia experiencia en ofrecer capacitación y asistencia técnica a organizaciones de salud y proveedores de servicios sobre la programación de los(as) promotores(as) de salud adaptada a sus necesidades específicas.
Strengthening Aging Services for Hispanic Populations

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Fortalecimiento de los Servicios para Personas Mayores para la Población Hispana

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Overview of Aging Services Program

Supported by the Administration for Community Living
Descripción General del Programa de Servicios para Personas Mayores

Centro de Recursos Técnicos para el Envejecimiento de las Minorías (TARC)

**Recursos**
- Material cultural y lingüísticamente apropiado
- Blogs
- Boletines
- Recursos

**TTA**
- Enfoque en los compañeros/promotores(as) de salud
- Llamadas mensuales de AT
- Solicitud de asistencia
- Oportunidades a futuro

**Aprendizaje Virtual**
- Webinars
- Aprendizaje Colaborativo
- Sesiones pregrabadas

Apoyado por the Administration for Community Living
Technical Assistance Calls?

• Provide **resources** and **training** on key issues affecting the Aging Hispanic/Latino community

• **Peer support**

• Collect **feedback** from service providers on future TTA topics
¿Llamadas de Asistencia Técnica?

- Proporcionar **recursos** y **entrenamiento** sobre problemas clave que afectan a la comunidad hispana / latina rumbo a la tercera edad.
- **Apoyo entre compañeros**
- Recopilar **comentarios** de los proveedores de servicios sobre futuros temas de AT
Introductions

NAME

LOCATION

ORGANIZATION
Introduucciones

NOMBRE
UBICACIÓN
ORGANIZACIÓN
Agenda

1. What is Hospice?
2. Hospice use among the Latino population
3. How to increase hospice use among Latinos
4. How CHWs can help
5. Resources
6. Funding opportunities
7. Questions/Discussion
Agenda

1. ¿Qué es Hospice?
2. El uso de Hospice entre los Latinos
3. Cómo aumentar el uso de Hospice con los Latinos
4. Cómo CHWs pueden ayudar
5. Recursos
6. Oportunidades de financiamiento
7. Preguntas y discusión
What is Hospice?

"Hospice care is a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.

...Hospice care treats the person and symptoms of the disease, rather than treating the disease itself. A team of professionals work together to manage symptoms so that a person’s last days may be spent with dignity and quality, surrounded by their loved ones. Hospice care is also family-centered – it includes the patient and the family in making decisions."

- American Cancer Society
¿Qué es Hospice?

"El programa de cuidados para el final de la vida (hospicio) es un tipo especial de cuidados concentrados en la calidad de la vida de la persona y de sus cuidadores, que se enfrentan a una enfermedad avanzada que limita la vida. El programa de cuidados para el final de la vida proporciona una atención compasiva a las personas en las últimas fases de una enfermedad incurable, para que puedan vivir tan plena y cómodamente como sea posible.

...Se trata a la persona y a los síntomas de la enfermedad, no se trata la enfermedad misma. Un equipo de profesionales colabora para controlar los síntomas, para que la persona pueda pasar sus últimos días con dignidad y calidad, rodeada de sus seres queridos. El programa de cuidados para el final de la vida también se centra en la familia, incluye al paciente y a los miembros de la familia en la toma de decisiones."

   - American Cancer Society
Difference between Palliative Care & Hospice
Cicely Saunders (1918-2005) Founder of the Modern Hospice

She was an English nurse, social worker, physician and writer.

Cicely is noted for her work in terminal care research and she had a very important role in the birth of the hospice movement, emphasizing the importance of palliative care in modern medicine.

She was a nurse who served her country in the WWII. After coming back to UK she suffered the death of her husband and her father that led her to decide to set up her own hospice, serving cancer patients. She understood that “as body becomes weaker, so the spirit becomes stronger.” In 1967, St Christopher’s Hospice, the world’s first purpose-built hospice, was established.

The hospice combined the principles of teaching and clinical research, they work in pain and symptom relief with holistic care to meet the physical, social, psychological and spiritual needs of its patients and those of their family and friends. Cecily liked to say to her patients “you matter because you are you, you matter to the last moment of your life”.

Hospice in USA

In 1969, Dr. Elisabeth Kubler-Ross published her groundbreaking book, On Death and Dying, which contains more than 500 interviews with dying patients. In this book, Dr. Kubler-Ross emphasizes the benefits of home care over treatment in an institutional setting for terminally ill patients, and argues that everyone deserves the right to decide about their end-of-life care.

In 1974, Florence Wald, two pediatricians, and a chaplain founded the first hospice in the US, The Connecticut Hospice in Branford, CT.

Today there are more than 4,400 hospices working in USA attending to more than 1.5 million people (2015). 63% of the hospices are for profit.

Whites make up 80% of those using hospice, African Americans 10%, and Hispanics 7-10%

Why is Hispanic use of Hospice Services so low?
Why don’t Hispanics use Hospices Services in USA?

• Hispanic living in USA are 44 million, Mexicans are the 64 % of the Hispanics living in USA.
• Of the 1.5 million people requesting Hospice Services only 7-10 % are Hispanics

Some of the reasons are:

1. **The Language barrier**: First generation of Mexicans living in USA only 23 % are reported to be able to speak English very well. The Palliative Care specialists in the country doesn’t speak Spanish at all.

2. **Lack of knowledge about hospice program**: The word Hospice in English is translated as Hospicio in Spanish and the meaning is a place to aid orphan children, a place for poor, old people or for people with disability.

3. **The Spanish patient and their family doesn’t want to talk about death**: The feeling is very similar to the way African American patients believe. Something is going to happen, my prayers will be here, and a miracle will happen then I’m not going to die. “Mientras hay vida, hay esperanza” (While there is life, there is hope).

4. When I was a child, my parents take care of me, now I’m proud of taking care of them. It’s not a way that I’m going to abandon them in this difficult moment.
San Diego Hospice: a story that ended bad!

...San Diego Hospice...

≈ 850 staff       ≈ 750 volunteers
Budget ≈ $80 million

Hospice Care
Prognosis < 6 months       Non-Hospice Care
Any time

≈ 4,500 new patients per year  ≈ 1,500 new consults per year

< 40% cancer, > 60% non-cancer
What is necessary to enhance the use of Palliative Care in the Hispanic population?

1. The main idea is to improve the access of the Hispanic to Palliative Care in USA because these services provide dignity to the End of Life (EOL) process.

2. Clinicians and other providers need to increase their cultural awareness/sensitivity to the Hispanic culture to improve the attention of the Hispanic population in hospices. Have more health professional working in Hospices fluent in Spanish. Use of Translator isn’t enough.

3. Latinos need to feel that it is possible to tell the truth to the patient—telling the patient about the prognosis is better than hide it from them. There are a lot of research that showed that when the patient know what is happening with their disease the cope it in a better way.

4. In some Latino families when the patient is a female, the male is the one who makes the decisions about her health. This is called machismo and it’s necessary to work to give the power of decisions to the female patient if she desire to do it.

5. There is a lack of information and communication about the benefits of use hospice in our community and because of this, a lot of patients are suffering pain and their symptoms at the EOL are not treated properly.

6. Since the approval of the Obamacare. Medicare and Medical paid 100% of the cost of the Hospice Services in California but most of the Hispanic population don’t have this information and it is one of the main barriers for them to use Hospice services.
Thanks for your attention to my presentation and I’m ready if you have a question about it!
The American Public Health Association has adopted the following definition of Community Health Worker

A Community Health Worker is a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the worker to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery.

A Community Health Worker also builds individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy.

In other words...

A Community Health Worker is a trusted member of the community who empowers their peers through education and connections to health and social resources.
La Asociación Estadounidense de Salud Pública ha adoptado la siguiente definición de Promotor y Promotora de Salud

Los(as) Promotores(as) de Salud o Trabajadores Comunitarios son aquellos que ocupan la primera línea de atención en la salud pública.

Son miembros en los cuales la comunidad ha puesto su confianza y que poseen un conocimiento único sobre la comunidad a la que sirven.

Basado en esta relación de confianza, los(as) promotores(as) se convierten en el enlace, son el interlocutor o intermediario entre los servicios de salud o servicios sociales y la comunidad, facilitando el acceso y la calidad de los servicios de salud y mejorando la atención culturalmente adecuada.

Además, Los(as) promotores(as) de salud desarrollan capacidades individuales y comunitarias al incrementar el conocimiento sobre la salud y la autosuficiencia a través de actividades, tales como: Promoción de Salud, educación comunitaria, terapia o consejería informal, apoyo social y abogacía.
Yes, last night at 12 o'clock [midnight] a white man knocked on my door and said he was a nurse that was here to help me; I was scared. I told him to go away, but he did not. I waited a little bit, looked through the peephole and there he was. I said, “Go away, go away.” I did not want to talk too loud. The next thing I knew, the phone rings and they were saying something, a lot of things I did not understand. Then I heard the word “hospice.” I did not know what they were saying so I hung up, I called my daughter quietly and told her about the white man at my front door passing for a nurse and the telephone call with somebody saying the word “hospice.” She said, “Mom, don't worry. I'll find out what this is about.” When I called her back, she [my daughter] said, “Let the man in because the hospice nurse ordered a night nurse.” I was so nervous; a man I don't know in my house with my husband being sick. My daughter remained on the phone with me and she said, “Mom, let him in. The hospice sent him.” He wanted to go into my bedroom and watch my husband sleep. I can't sleep with a stranger watching me. My daughter spoke to him and told him to sit in the living room. He sat down. I went to the room but I could not sleep knowing there was a stranger in the house. When it got light outside I sent him home. I felt bad. I don't want to take food out of his mouth but I was so tired I could not sleep with him sitting in the living room.
What does the research say?

- *Familismo* and family-centered systems influence decisions about Hospice\(^1\)
- Hispanic individuals do not want to discuss terminal prognosis making conversations about Hospice use difficult\(^1\)
- Latinos more likely to enroll in Hospice during hospitalization/crisis than before crisis\(^1,4\)
- Talking openly and bluntly about death is upsetting with his population and not a culturally appropriate strategy\(^1\)
- Family members fear telling dying individual about their prognosis will make them worse/cause harm; family makes decisions to protect individual\(^1\)
- There is a lack in culturally competent Hospice staff\(^2\)
- Patients are concerned about staff not speaking Spanish\(^2\)
- Bilingual staff experience burnout\(^2\)
- Misunderstandings about what Hospice means/language barrier\(^3\)
- Misunderstanding about services, feel like abandoning family\(^3\)
- Distrust in provider/healthcare system\(^5\)
- Poverty, immigration status, lack of insurance also influence Hispanic individuals’ ability to enroll in hospice\(^6\)
¿Qué dicen las investigaciones?

- **Familismo** y un sistema centrada en la familia influye decisiones sobre Hospice¹
- Individuos hispanos no quieren hablar sobre un pronóstico terminal, lo cual hace conversaciones sobre Hospice difícil¹
- Los latinos son más probables de inscribirse para Hospice durante un crisis/hospitalización que antes del crisis¹,⁴
- Hablar libremente y francamente sobre la muerte es sorprendente para esa población y no es una estrategia apropiada con esa población¹
- Miembros de la familia temen decir al ser querido sobre sus pronóstico va a hacerle peor o causarle daño; la familia toma decisiones para proteger a esa persona¹
- Hay una falta de personal en Hospice que sea culturalmente competente²
- Pacientes preocupan que el personal no habla español²
- Personal bilingüe experimentan agotamiento²
- Mal entendidos sobre qué significa Hospice/barrieres de idioma³
- Mal entendido sobre los servicios de Hospice, se siente que está abandonando a su familiar³
- Desconfianza en los proveedores/sistema de salud⁵
- Pobreza, estatus migratorio, falta de seguro también para hispanos influyen la habilidad de inscribirse para Hospice⁶
Sources/Fuentes

1. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3570252/
2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3965263/
CHW’s & Hospice: How they can help

• Educating the community!
• Discussions with patients and healthcare proxies
• Discussions about end of life wishes and advance directives in culturally appropriate manner
• Build trust and have compassion
• Provide referrals and warm handoffs
• Inform palliative care providers on cultural and language influences affecting care
• Advocate for patients and caregivers

Promotores y Hospice: Cómo pueden ayudar

- Educar la comunidad!
- Hablar con pacientes y sus agentes/apoderado(a) de atención medica
- Hablar sobre deseos del final de la vida y la planificación anticipada de decisiones en una manera culturalmente apropiada
- Generar confianza y tener compasión
- Proveer referencias y transferencia cálida
- Informar los proveedores de cuidados paliativas sobre influencias de cultural y idioma que pueden influir el cuidado de un paciente
- Abogar por pacientes y cuidadores familiares

Funding Opportunities / Oportunidades de Financiamiento

1. Administration on Community Living (https://www.grants.gov/web/grants/view-opportunity.html?oppId=330122) funding for research and documentation of innovative practices that have the potential to enhance nutrition services programs within the aging services network. Estimated post date is March 29, 2021.


3. Michigan Health Endowment Fund Healthy Aging program https://mihealthfund.org/grantmaking/healthy-aging "We support projects that improve access to care, allow Michigan residents to age in place, and help communities build a culture of emotional support for older adults." Applications open summer 2021.

4. HHS https://www.grants.gov/web/grants/search-grants.html Funding to address culturally appropriate community education on topics like elder abuse, neglect and exploitation among Native populations. Forecasted to post 4/1/21.
Other Helpful Resources / Otros Recursos Útiles

✓ Hospice Foundation of America – Spanish Language Resources: https://hospicefoundation.org/Hospice-Care/How-to-Choose/Spanish-Language-Resources

✓ American Cancer Society – Hospice Care: https://www.cancer.org/treatment/end-of-life-care/hospice-care.html

✓ Relevant Articles on Hispanics and Hospice:
  ✓ “The Worst Thing about Hospice is That They Talk about Death”
    https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3570252/
  ✓ A Case Study of Hispanics and Hospice Care
    https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3965263/
  ✓ AARP: Latinos’ Hospice Use Is Growing
  ✓ When Do Latinos Use Hospice Services? Studying the Utilization of Hospice Services by Hispanics/Latinos
  ✓ Integrative Review of the Literature on Hispanics and Hospice
    https://journals.sagepub.com/doi/10.1177/104990917730555
  ✓ Stanford School of Medicine: Hospice, Dying and Death:
Thank you! / ¡Gracias!

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**You will find a link to the feedback from in the chat.**