



Palliative and End-of-Life Care for Latino Migrants

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SUFFERING

...is not feeling whole – not feeling one's 'personhood' as being intact

PALLIATIVE CARE

...aims to support the person & family facing a medical illness (usually advanced, terminal) who might have such suffering

How Things Have Changed

1900

- alcohol, morphine, aspirin, and digitalis are state of the art
- Causes of death: pneumonia, influenza, other infection inc. tuberculosis, enteritis (dehydration), heart attack, stroke
- **90% of deaths due to acute illness.**

Science Marches On

- 1905: EKG
- 1910: Band-Aids, stainless steel
- 1920s: Insulin
- 1940s: Penicillin
- 1950s: Chemo, Radiation, Vaccines (polio/measles)
- 1960s: Ventilators, CPR, ICUs, Dialysis, Cardiac Bypass
- 1970s on: CT scan, MRI...

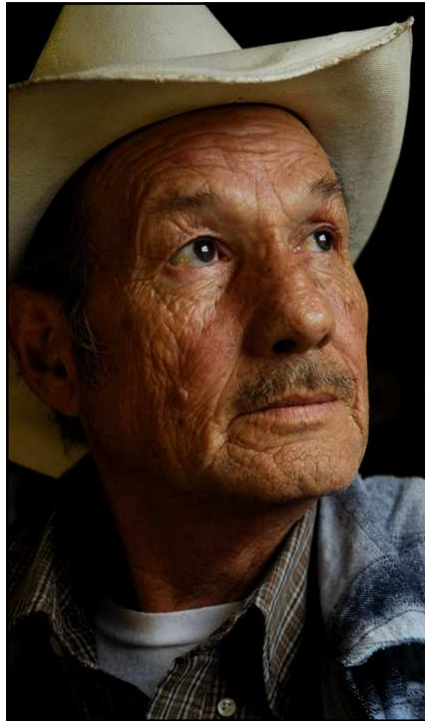
Adapted from Lissman, M.D.

And we die from different things

- Chronic heart disease
- Chronic pulmonary disease
- Complications of diabetes and hypertension
- Strokes
- Cancers
- Neurologic diseases
- Accidents – some with long, extended courses



~90% of us now die from chronic illness



Advanced Illness in Older Adults

- Greater medical complexity in older adults.
- 75% of cancer deaths occur > 65 years of age.
- Heart failure identified in >10% by age 70+.
- Dementia: affects 6-10% of age 65+ and 30% of age 85+. Median survival after diagnosis is 8 years

Caregiver burden and risks

- Caregivers are shouldering increasing burden of longer trajectory of advanced illness.
- Many studies document health risks to caregivers, esp. elderly spouses.
- Caregiving in *dementia* cases is especially challenging.



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Essentials of Palliative Care

- Bridge patient's goals with medical options
- Address all aspects of pain and suffering: physical, emotional, spiritual, social
- Maximize quality of life
- Assist in search for meaning
- Help to achieve goals, dreams, aspirations
- Help transition: from health to illness, to death, to bereavement
- not incompatible with prolonging life or seeking reversals, remissions, slowing of disease

What is hospice?

- Specialized end-of-life services for patients with an expected life expectancy of < 6 months (Medicare benefit)
- Primarily community-based
- Care for terminally ill patients and their families provided by an interdisciplinary team of professionals and trained volunteers
- Goals:
 - ▶ relief of pain and other symptoms
 - ▶ psychosocial support

Hospice care offers...

- Patient control over decisions about care
- Family & caregiver support & involvement
- Specialized services
Option for patient to die at home



What people value in hospice care

- Pain & other symptoms managed well
- Death not inappropriately prolonged
- Sense of control
- Opportunities & support to have closure

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Evolving Concepts of Palliative Care

Old



New



Lissman; many others

The Team



Some cultural considerations

- Life expectancy, disability may be different for Latino migrants
- Caregiver burden may be experienced and construed differently
- Cultural expectations around “doing everything possible” vs. medical treatment actually being burdensome may be underpinned by particular issues of mistrust and fear (abandonment, etc)
- Palliative care is new to countries of origin, including (in most countries) hospice concept
- Cultural differences around patient autonomy and medical authority may exist

Autonomy



Ethical Considerations

- Autonomy
- Beneficence
- Honesty
- “Do no harm”
- Do the right thing
- Justice issues-disparities

Autonomy

- Individualism
- Right to refuse
- Capacity
- Substituted judgment
- Advanced directives
- DNR and withholding, withdrawing

Prognostication

- Ethical principles of beneficence and non-maleficence- Do no Harm- should make caregivers think and hesitate on direction of care
- Step back , look at patient from afar
- Goals of care
- Futility
- Nothing we can do-
- Diagnosis of dying

Prognostication

- Honesty
- Accepting uncertainty
- Prepare for sudden death
- Surprise is not acceptable if avoidable
- Allowing decision making and planning to take place

Symptom Management

- Pain
- Nausea
- Breathlessness
- Fatigue
- Depression
- constipation

Assessing pain is not always straightforward...



Communication

- Who starts it
- How to set it up
- Telling bad news
- Language used
- Words used
- A process not a one time thing

Communication

- Listen
- Listen actively some more
- Avoid lines that set up adversarial relationships
- Find common goals
- Listen some more

Strengths of Migrant & Immigrant Communities



Latino migrants and immigrants

- Latino ↔ non-Latino important, but:
- Complicated set of cultures full of individuals!
- Cultural proficiency
- Socioeconomic proficiency
- New Growth Communities
- Immigration status and insurance status as determinants of access



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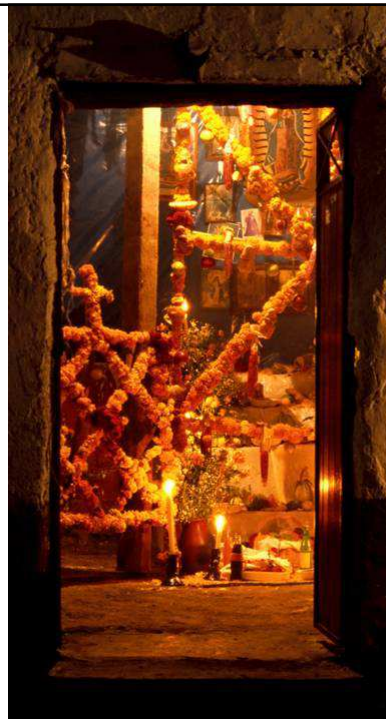
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Latino immigrants

- Tend to be in low-wage, high risk employment
- Likely from rural interior and southern Mexico, limited education and English
- Uninsurance may be 80% +
- Elders often ineligible for Medicare
- Emergency Medicaid doesn't cover hospice or palliative care

Typical practices and beliefs

- Spirituality, faith, strong belief in power of prayer, sanctified or personalized objects
- Fatalism, resignation, stoicism
- Christians a very large majority in all nationalities





- Spanish dominant but not sole language (Miztec, etc)
- Family, not individual, the unit; extended family & even ancestors
- Esp. in Mexico, a very mixed approach to death and the dead

Mexican Días de los Muertos...



The Mexican, explains poet Octavio Paz, not only shrugs at death, but he "...chases after it, mocks it, courts it, hugs it, sleeps with it; it is his favorite plaything and his most lasting love."

- Hospitals = feared (“place to die”) +/- enormously trusted (“place for cure;” miracles performed)
- Some misunderstandings regarding terminal illness: TB, cancer vs. CHF, emphysema
- Beliefs about telling diagnosis and/or prognosis may differ from medical culture

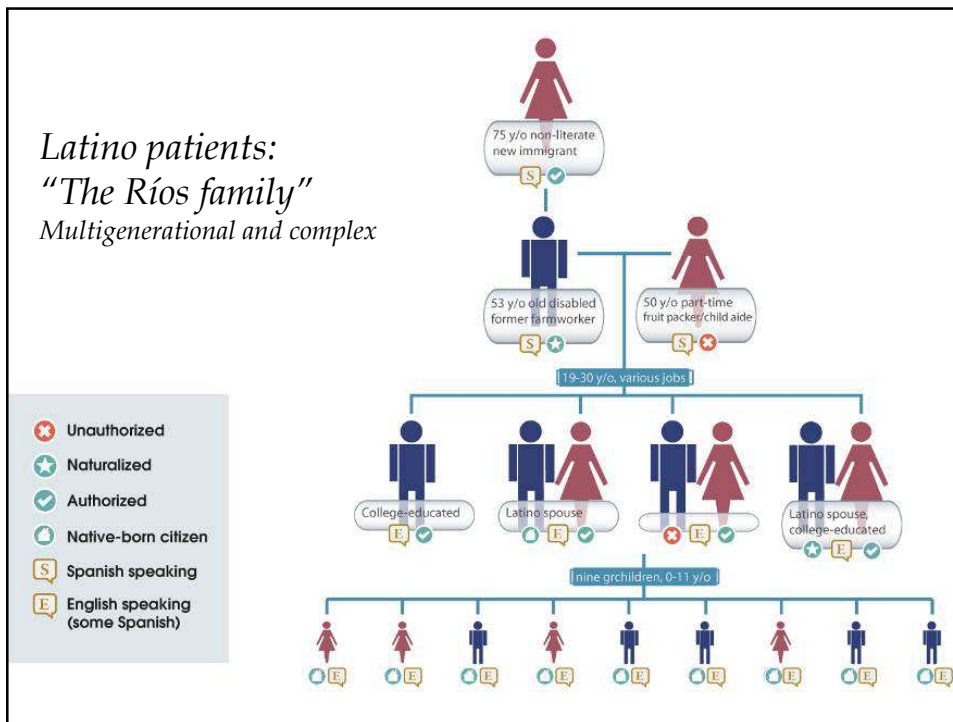


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Unfamiliar terms



*Latino patients:
"The Ríos family"
Multigenerational and complex*



"Doña Elena"

75 y/o non-literate new immigrant ♀

- Spanish-speaking only
- Authorized legal resident
- From a 'ranchito' near Morelia, Mexico
- Never hospitalized
- On first checkup in 5+ years, has large breast mass, enlarged firm axillary nodes, R humeral pain 9/10 since turning in bed 2 days ago



Photo courtesy of Tia Eca

“Doña Elena”

- What is her likely diagnosis?
- Does she have Medicare or Medicaid?
- Can she get Medicare or Medicaid?
- What will Emergency Medicaid cover, and where? What won't it cover?

“Doña Elena”

Her family will likely say:

- (a) Please don't tell her dx or px
- (b) Please do everything you can to save her (no matter the cost)
- (c) We will take care of her ourselves

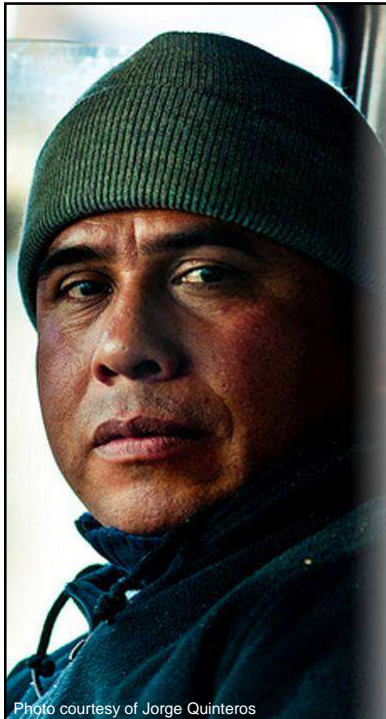


Photo courtesy of Jorge Quinteros

“Señor Ríos”

*53 y/o disabled former
farmworker*

- Spanish preferred
- Naturalized US citizen, 35 yrs
- From a pueblo near Leon, MX
- Injured on the job 7 years ago; uninsured
- MS dx'd 3 years ago; recent exacerbations and complications; now in wheelchair; comorbid COPD; 3 ER visits past 7 mos.

“Señor Ríos / Mr. Ríos”

- He is not on Medicare nor SSI. Applied 3 mos ago. How long until determination?
- He's not on Medicaid – state plan shrank, not covering adults w/o dependent children.
- Family can't afford High Risk Pool coverage.
- Primary care home = community health center.
- Local hospital provides some charity coverage.

“Señor Ríos / Mr. Ríos”

He may feel:

- “I want everything done.”
- “I don’t want to leave my family in debt.”
- “This is a punishment I must accept.”
- “This is unfair, after how hard I’ve worked.”

He may need, but deny that he needs, interpretation/translation. He may not complain of pain.



“Señora Ríos”

50 y/o part-time fruit packer/child aide

- Unauthorized, in US for past 19 years, beginner’s English
- Uninsured, gets primary care
- Sudden autoimmune hepatitis. Within 6 years on multiple medications, develops diabetes requiring insulin, osteoporosis with several fractures, chronic pain, both knees and hips replaced, depression, PUD, chronic anemia

Photo © Alan Pogue

“Señora Ríos”

- Can she get Medicaid?
- What will Emergency Medicaid cover?
- Can she be on Home Health?
- *What assets can she draw upon for her palliative care?*

“Señora Ríos”

- Her greatest fears likely relate to losing her caregiving ability (grandchildren, husband, mother).
- She may moan but deny pain.
- She may lack faith in, or fear, medication.
- She may not feel confident or permitted to speak for herself.
- She is very likely to be using traditional remedies.
- Her greatest pain may be spiritual/ existential (and relate to homeland and family away).

Remember family
conferences!

Remember sub-family
conferences!

What Works?



Photo © Kate Bero

Identify what we need to learn

- *Range of beliefs and practices about incurable disease, dying, death and bereavement*
- Preferred/acceptable terminology and approaches
- Aversions, potential offenses
- Obstacles, fears (inc. of utilizing care)
- Natural leaders, partners to help disseminate information
- Knowledge of existing resources

Community Health Workers

- Also known in Spanish as *promotoras* or *promotores de salud* (health promoters)
- Utilized all over the world
- *Underutilized* in hospice & palliative care in the US, and in migrant and community health centers with respect to advanced disease, death and dying





Providence Hospice of The Gorge: one example: Hispanic Outreach Program

- United Way grants – 1 yr, renewed a 2nd yr
- CHWs from C/MHC & health dpts
- Surveys, focus groups, presentations
- Inservice: Board and staff X 2 in first year
- Spanish-speaking interdisciplinary team
- Spanish immersion training sponsored
- Spanish language materials created
- Spanish language phone response launched
- Referrals from and to community partners

Before and after (outcomes)

- 1981-2006: 2 Spanish-speaking families served
- Since 2006 (inception of Hispanic Outreach Program and work of the CHWs): 17 Spanish-speaking families served by Hospice &/or palliative care.
- Almost all patients = immigrant MSFWs.



Please evaluate...

- <http://www.migrantclinician.org/survey/fillsurvey.php?sid=82>
- Please help us continue to provide webinars and complete the evaluation
- Must complete evaluation to receive CME/CNE
- Thank you!

