

Hope for Hispanic Patients In the Context of Hospice

Alberto Magana, DMin
Alberto.magana@vitas.com
Vitas Innovative Hospice Care
Dallas, TX

GOAL

To Develop Cultural Sensitivity by
Examining how The Narratives of Future
Oriented Stories of Hope Impact the
Experience of Anticipatory Grief for
Hispanic Hospice Patients

OBJECTIVES

1. Discuss challenges faced by Hispanic patients and hospice providers when presenting hospice services.

2. Explore the anticipatory grief process and the stories of hope of six Hispanic hospice patients through *narrative approach*

3. Identify an appropriate pastoral response to discuss spiritual beliefs for hospice patients by respecting their cultural understanding and developing a functional story of hope

1. Challenges Faced by Hispanic Patients and Hospice providers when Presenting Hospice Services



Story of Maria
Denial or hope?

Hospice staff “challenge”

Understanding the expectation of a miracle when the patient was unresponsive

What’s the role of hope?

Qualitative Research

This information was developed in conjunction with 5 years of study, research , hospice work, and my observations on how Hispanic hospice patients struggle & cope at the end of life.

Hispanics in the United States

Census 2010, population increased from 35.3 million people to 50.5 million; 16% of the entire population in the USA.

According to NHPCO, 94.7% were non-Hispanic origin. Only 5.3% were Hispanic

ADMISSION OF HISPANIC PATIENTS TO HOSPICE PROGRAMS REMAINS LOW

- **What keeps Hispanic patients from approaching hospice services?**
- **Is hospice a model of end-of-life care that truly appeals to Hispanics?**
- **Once Hispanic patients have been admitted into hospice services, how do we make these services more culturally sensitive to their understanding while making sure the care they receive more appropriately matches their cultural context?**

Cultural Beliefs Affecting End-of-Life

- I have to accept it because God allows it to happen/I can change God's plan if I have enough faith
- Negative meaning of hospice
- Avoid end-of-life conversations and prefer continuity-of-life
- When from a medical perspective there is no more treatment, most of the Hispanic patients turn to God for healing and expect a divine intervention
- Difficulty understanding the difference between comfort care and aggressive treatment

What kind of language can hospice providers use to present hospice services as an end-of-life model without being disrespectful to the values, culture, and belief system of Hispanics?

❖ **Experience**

❖ **Culture**

❖ **Tradition**

EXPERIENCE



Patients: Research with 6 particular patients using narrative approach exploring the present, past, and the future by looking for meaning

Future Tense



The future provides the most important clues to a person's identity. We project ourselves into the future.

Questions Exploring the Future

1. Do you have any hopes?
2. What does "hope" mean to you?
3. How do you see your future?
4. How does your future change over time?
5. As you think of your future, what feelings or emotions are you experiencing?
6. When looking towards the future, what image of God do you keep in mind?
5. What do you think will happen to you when you die?

Questions Exploring the Present

1. How do you describe what is happening to you now?
2. How is this affecting you and what are you experiencing?

Questions Exploring the Past

1. How did you come to understand "hope," "death", "God" in the way you do? Is this understanding helping you?

CULTURE

- **Traditional** view of death from a **Modern** perspective or **Postmodern** view of dying?
- **Anticipatory Grief** vs **Waiting Experience**

Traditional View of Death

- Death is seen as a medical event where biological existence takes over the spiritual dimension of human existence
- Human functionality as a machine: people need to recover from their state of intense emotionality and return to normal functioning as quickly as possible
- Certain steps and actions need to be followed like a linear movement which contains stages toward a final stage which is the acceptance of the loss

Postmodern View

- Individual respond to dying, death and grief according to what they have learned at home and within their own culture
- Every culture has different concepts that create meaning for their dying experience and what happens after death
- Usually the dominant culture has the tendency to interpret dying and death into its own perspective
- Concerned with meaning more than facts and rules. Realities are socially constructed therefore there are no essential truths

TRADITION

- Judgment after death as well as a reward according to how a person has lived his/her life
- Three possible places after death: Heaven, Purgatory, and Hell
- The fear of dying makes them do everything possible to postpone the reality of death

2. Anticipatory Grief Process and the Stories of Hope of 6 Patients



A Narrative Approach

WAITING EXPERIENCE WITH STORIES OF HOPE: "FULL OF LIFE"

Raul and Antonia

- Full of life in the present
- Full of life in the future

- Power of Hope to overcome any difficulties of life. They learned from experience-past to create a *Sacred Story of Hope* and to understand that suffering is an opportunity to hope.
- They enjoyed their story-present with their families and accepted their terminal condition. They waited patiently to enjoy the fullness of life after their death. A life with the certitude that they will be with God.

WAITING EXPERIENCE WITH STORIES OF HOPE: AMBIGUOUS – MULTIPLE STORIES PRODUCING LIMITED LIFE

- Pedro's Waiting Experience
- Jose's Waiting Experience
- Maria's Waiting Experience
- Ambiguous life in the present: depression, suicidal thoughts, anxiety, and happiness
- Ambiguous life in the future: *Heaven for me?*

- Hope changed overtime
- Different types of hope
 - Minor or Major
 - Human or Divine
 - Natural or Supernatural
- Disconnected Hope: *Sacred Story* unfinished
- Meaning of Salvation: good works

Am I doing enough to go to heaven?

WAITING EXPERIENCE WITH STORIES OF HOPE: "NO LIFE"

Jorge's Waiting Experience

- Fearful, Depressed, Lonely in the Present
- Fear of Hell in the Future
- Unwanted Waiting Experience
 - *"Help me to believe in something so my dying can be easier"*
- Concept of God

3. Appropriate Pastoral Response to Discuss Spiritual Beliefs for Hospice Patients by Respecting their Cultural Understanding and Developing a Functional Story of Hope

Use of Narrative Theory

- The waiting experience (anticipatory grief) varied according to their construction and understanding of the concept of the future-oriented-story-of-hope
- These conversations empower patients to explore their journey of life from their own cultural perspective

- Through the use of narrative conversations patients are able to describe their own journey not only from the past but also the perception of the future
- Patients turn to hope as something that allows them to find healing and connections and to maintain conversations about the continuation of life

- The telling of the story to a non-judgmental professional caregiver enables the patients to construct new meanings that may alleviate their suffering by identifying their own resourcefulness.
- By questioning, professional caregivers provide for the patient the opportunity to explore various dimensions of their stories

- Narrative theory postulates that our stories constitute our reality and identity. We make meaning through language. If our narrative is not helpful, we can change our narrative in order to change the reality.
- Any kind of hope is hope. Hope can be expanded, transformed, and redefined but not taken away.
- Professional caregivers can assist patients/families in the creation of a *Sacred Story* where human hopes are connected with the *Divine Hope*, integrating the dying experience.

Conclusion

I strongly suggest that it is important for professional caregivers to have an understanding of the cultural context when providing care for Hispanic hospice patients. Narrative Theory provides a framework to co-explore the context and assess the journey of life with these patients so we can join them in their journey without taking the role of the expert.

For Hispanic patients the anticipatory grief process becomes a *Waiting Experience* using *hope* as a way of coping and connectedness. When these patients transform the waiting experience into a experience of hope, they are transformed as hope changes overtime giving them the possibility to enjoy the fullness of life in the present and in the future.

Any belief system can be challenged, transformed and reinterpreted by the patients as they face the *Waiting Experience* because they deserve the freedom to experience the fullness of life in the present and after their death.

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For complete access to my works search the internet for:

"Hope for Hispanic Patients in the Context of Hospice: The Impact of Narratives of Future Oriented Stories of Hope in the Experience of Anticipatory Grief for Hispanic Roman Catholic Hospice Patients in the Fort Worth Area"

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