Denial or Hope?

*When a Patient and Doctor Disagree at the End of Life and a Pastor is in the Middle*

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Objectives

1- Discuss some challenges engaging patients in the end of life conversations when they prefer continuity of life

2- Describe how hope fits in with the end of life care for Hispanic patients in a multicultural and post-modern world

3- Engage patients and families in end of life discussions from limiting/curative to limitless/palliative
INTRODUCTION

This information was developed in junction with 5 years of study and research at Texas Christian University, 10 years of hospice work, and my observations on how Hispanic hospice patients struggle & cope at the end of life.
1. Discuss challenges engaging patients in the end of life conversations when they prefer continuity of life

“I do not want anyone giving up on me”
END OF LIFE CHALLENGES

- Delivering the bad news
- Frustrated?
- Honoring patient’s wishes
- Understanding each other
- Are you missing the point?
- Understanding the expectation of a miracle
- Who else is in the room?
- Too late for this conversation?
What kind of language can medical professionals use to present hospice services as an end-of-life model without being disrespectful to the values, culture, and belief system of patients and families?
How can I identify, acknowledge, respect and include the invisible person who is present in the room and has a great voice?

Bridging the Gaps between Physician, Patient and Pastor (Spiritual Beliefs)
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

- Belief: “I have to accept it because God allows it to happen but I can change God’s plan if I have enough faith”

- Popular Religiosity: Born of the people, an expression of the culture

- Negative meaning of hospice

- Role of the family and community
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
2. DESCRIBE HOW HOPE FITS IN WITH THE END-OF-LIFE CARE FOR HISPANIC PATIENTS IN A MULTICULTURAL AND POST-MODERN WORLD
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.
DYNAMICS OF HOPE

- False hope
- Giving up hope
- Realistic hope
- Unrealistic hope
- Human hopes
- Earthly hopes
- Divine Hope
- Hope is hope
- Hope changes over time
DYNAMICS OF HOPE

- How hope becomes a vehicle to assist the patient and family to navigate end-of-life
- Anticipatory grief can be experienced through hope

Hope contributes to the construction of the Sacred Story where the dying experience is located

Hope is a coping mechanism

Human hope alone does not help at the end-of-life
3. ENGAGE PATIENTS AND FAMILIES IN END-OF-LIFE DISCUSSIONS FROM LIMITING/CURATIVE TO LIMITLESS/PALLIATIVE.

“What matters to me at the end of life”
Future-Past-Present connected producing life and joy.
- 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

- Ambiguous life in the present: depression, suicidal thoughts, anxiety, and happiness
- Ambiguous life in the future: *Heaven for me?*
- Ambiguous life in the past
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?*
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
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?
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 an experience of hope, they are transformed as hope changes over time, giving them the possibility to enjoy the fullness of life in the present and in the future.
Bibliography of Key References:


Carrigan, Robert L. “Where has Hope Gone? Toward an Understanding of Hope in Pastoral Care.” *Pastoral Psychology* 25, no. 1 (September 1976).


Stone, Howard and Andrew Lester, “Hope and Possibility: Envisioning the Future in Pastoral Conversation” *The Journal of Pastoral Care*, 55, no. 3 (Fall 2001)


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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