Compassionate Communication at End of Life: Construction of an Interhuman Connection

UNCG Gerontology Research Network

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Agenda

- What the literature says about end-of-life communication
- Research findings on impressions of Hospice
  - Cultural contexts related to end-of-life communication
  - Impressions of Hospice
  - How Hospice constructs humanness for patients and families
What do we know about end-of-life communication?

- An impending death forces people to let go of everything but the most important things in life (Keeley, 2007).
- People who are dying and their loved ones have an opportunity to find meaning through conversation in the face of impending mortality (Keeley, 2007).
End of life communication can:

- Strengthen close relationships
- Deal with the past and talk about things they couldn’t talk about previously
- Chance to share important moments
- Say a meaningful and heartfelt goodbye
- Opening to acknowledge fears and concerns about death and about a life without one another
- Last opportunity to forgive past hurts, deepen their love, and resolve conflicts
- Allowing opportunity to achieve closure in relationships

(Keeley, 2007)
One of the most important needs of the dying person is to feel heard and to maintain human connection (Vora & Vora, 2008).

Our ability to listen to the dying is often clouded by fear, confusion, helplessness, and guilt (Vora & Vora, 2008).
Tensions in what kinds of communication families want:
- They want to know the doctor’s prognosis
- They also want to hear hope
- They want guidance in interpreting doctor’s communication
- Even when they want the information, they can feel overwhelmed and ill-prepared to make necessary decisions

(Russ & Kaufman)
Families felt let down by doctors’ failure to take change of the situation by being clear about prognosis and making recommendations for palliative care.

- Most physicians wait for the family to bring up the topic.
- Conversations may take place with patient and family may be left out (Russ & Kaufman)
Death: The Beginning of a Relationship

- Objectives:
  - Where “humanness” and “personhood” (versus “patienthood”) are found in the interconnection between hospice team members and patients and families.
  - The moments in which the humanness of the terminally ill person is socially constructed through communication.

- 8 months of fieldwork in interdisciplinary team at LifePath Hospice
  - Interspersed with my story of my father’s experience as a hospice patient
Death: The Beginning of a Relationship

Fifteen years ago, my father died of a terminal illness. His illness profoundly changed our relationship, my relationship with my other family members, and my relationship with myself. At the time, I longed for a book that would help me understand what I was going through, and not finding one, vowed to write one someday. This manuscript intertwines my personal story of my father’s death with the story of my ethnography of a hospice organization. I wrote this work as an evocative narrative that seeks to understand and explain the process of communicating with the dying—and their families—and the ways that this communication potentially reinforces and enhances the humanity, life, and sanctity of relationships. This book takes a social constructionist approach to examine communication with and about people with terminal illness, and in so doing, illustrates and explains health communication theories in an understandable, concrete manner.

The thesis of the book is that while some end-of-life communication helps maintain the humanness of the dying person (see Bogdan & Taylor, 1989 for a discussion of social construction of humanness), and with it, the essential relationship between the dying and their loved ones, not all end-of-life communication accomplishes this. In our culture, when we see a person as being less than fully healthy, we also see them—and treat them—as being less than fully human (Kalish, 1981). Research suggests that Hospice helps facilitate the process of treating patients as persons through the way they think about, interact, and communicate with their patients. The main focus of this narrative manuscript is to examine and describe the places where hospice staff, patients, and families interconnect as persons beyond their social and patient roles.

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Navigating Dialectical Tensions

- Loyalty to institutional needs versus loyalty to patient needs;
- Balance between giving versus burnout;
- Communicating about life versus communicating about death.
How Hospice Constructs Humanness

- Holistic view of patients
- Care with dignity, agency, responsibility
- Unqualified caring
- Reciprocity of relationships
- Care as friendship
- Patients as worthwhile human beings
- Compassionate honesty
- Connecting the spiritual and the human
- Hospice care as a calling
- Dialogic connections
Dialogic Connections

- Moments of deep (interhuman) connection and understanding;
- Accept, confirm, acknowledge patients and families AS THEY ARE;
- Reciprocity of sharing and listening;
- Unconditional positive regard;
- Willingness to be vulnerable.
Other Work


- Smooth spaces (flexible, ambiguous, uncertain) (Bleakely, 2013)
  - Weick’s loose coupling
- Balancing life and death
- Balancing hope and hopelessness
- Balancing power and empowerment
Other Work

  - Tension between rhetorics of decay and resurrection
  - Cemeteries as spaces of life AND death
  - Respecting the wildness, unshackled, un-whitewashed spaces
Davis, C. S., & Crane, J. L. A dialogue with death: Horror films as a discursive attempt to construct a relationship with the dead.

- The importance of constructing a dialogic relationship with death.
- Horror films help us do that:
  - Let us ‘play’ with death in a safe space
  - Give us a tangible enemy
  - Show us that some things are worse than dying
  - Remind us that we have to go through the darkness to get to the light
Other Work

  - Eulogies are a site of identity construction
    - For the deceased (ultimate in retrospective sensemaking)
    - For the survivors (re-construction of self in the face of loss of the deceased)
    - Construction and reconstruction of relational identity
Other Work

Davis, C. S. “Ghost Hunting 101”: Science and the paranormal.

- Dialectical tensions between science and existential discourse
- Construction of our cultural beliefs about life and death