

BARNABAS HEALTH

What Matters Most at the End of Life

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Cultural Relevance in End-of Life Care

- The challenges with end-of life conversations may be influenced by numerous variables:
 - Provider's training
 - Provider's comfort
 - Adequate time
 - Patient's cultural norms vs Provider's cultural norms
 - Degree of acculturation of the patient
 - Language skills
- Keep in mind that patients are individuals!

Cultural Competency: an ongoing commitment and active engagement

- Cultural Desire
- Cultural Awareness
- Cultural Knowledge
- Cultural Skill
- Cultural Collaboration
- Cultural Encounter

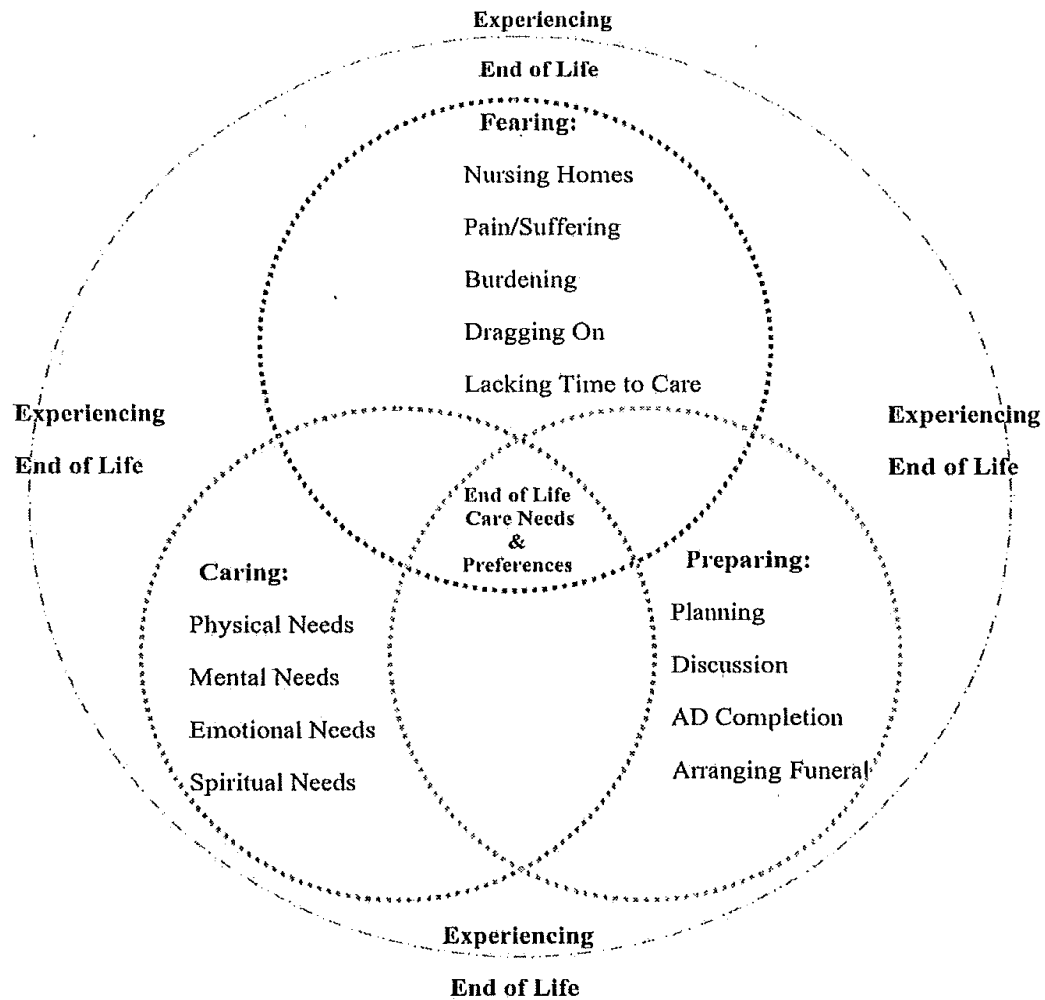


Figure 1. Older adult EOL care needs and preferences: The BSP; experiencing end of life.

Patient's Wishes at the End of Life

- 5 Domains are repeated throughout the literature:
 - Adequate pain management
 - Avoidance of prolongation of life
 - Achieving a sense of control
 - Relieving burden on loved ones
 - Strengthening relationships with loved ones

End of Life Care in New Jersey

- “The Dartmouth Atlas of Healthcare provides evidence that strongly supports the conclusion that N.J. patients experience more aggressive care at the end of life without evidence to suggest that there is a corresponding medical

End of life Care in New Jersey Hospitals: A Blueprint for Action NJHA

Dartmouth Study

- ❑ End of Life care discussions are often polarized, framing patients choices as cure vs. care, hospital vs. hospice, and life vs. death
- ❑ Living well has a different meaning for each patient, and it is the responsibility of clinicians and health care systems to help patients articulate their goals for living and for the medical care

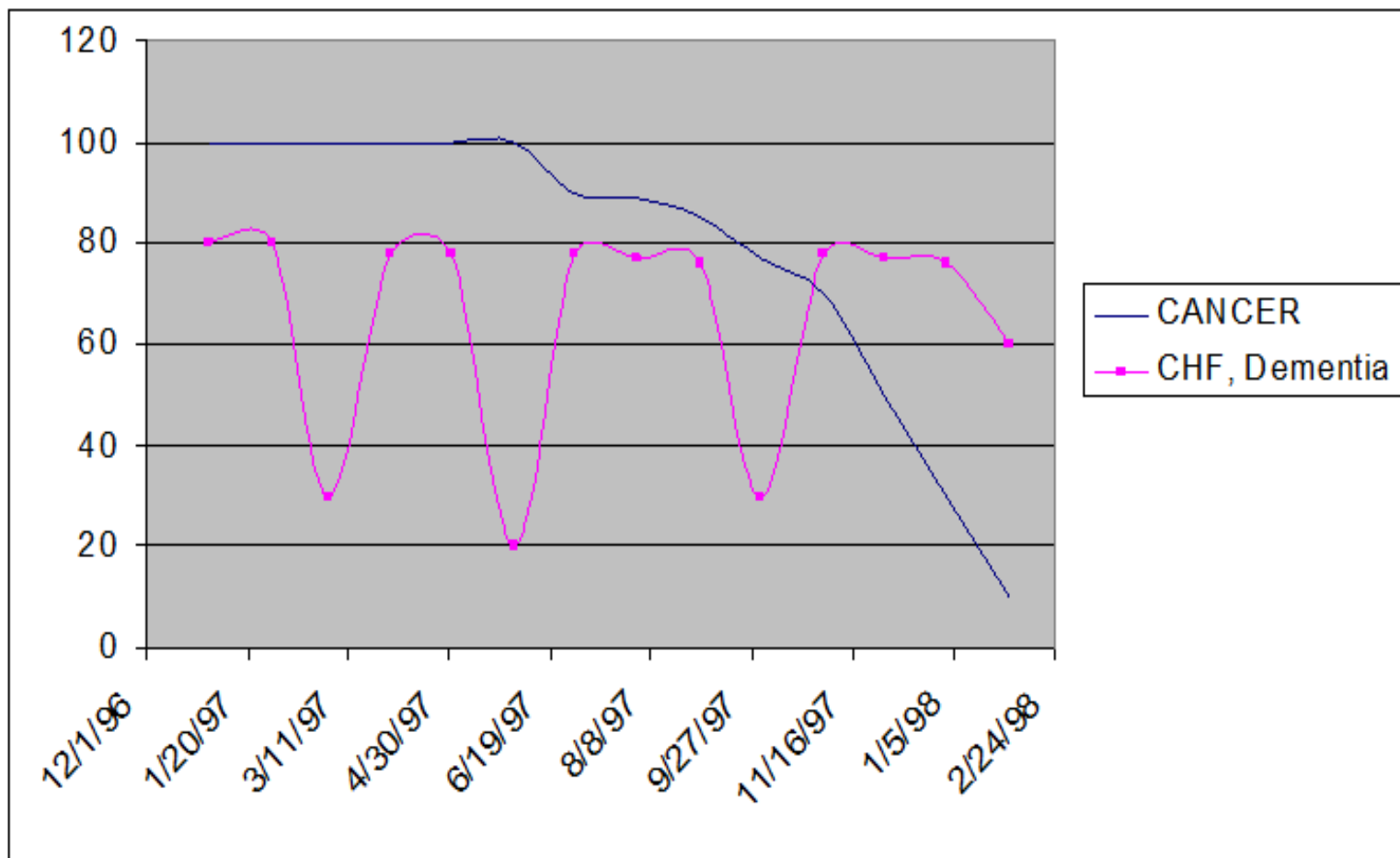
Dartmouth Study

- ❑ The study reflects “false assumptions about patient wishes, the difficulty of having serious conversations about end of life issues and at times, a failure to listen to the hopes and fears of patients and their families”.
- ❑ “Palliative Care early in the course of cancer illness can reduce discomfort from the disease and curative treatments and also legitimize the discussions of quality of life”.

SUPPPORT: Phase 1 Results

- 46% of DNR orders were written within 2 days of death
- Of patients preferring DNR, <50% of their MDs were aware of their wishes
- 38% of those who died spent >10 days in ICU
- Half of patients had moderate-severe pain >50% of last 3 days of life

The Last Year of Life



Periodic Crises, Sudden Death



Caring through life's end: Healing versus Curing

- What do patients with life-limiting illness want?
 - Pain and symptom control
 - Honest information
 - Avoid inappropriate prolongation of the dying process
 - Achieve a sense of control
 - Relieve burdens of family
 - Strengthen relationships with loved ones
 - Not cure
 - Not longevity
 - Attention to hygiene and grooming

Caring through life's end: Healing versus Curing

□ What Do Family Caregivers Want?

- Loved ones wishes honored
- Inclusion in decision processes
- Support/assistance at home
- Practical help (transportation, medicines, equipment)
- Honest information
- 24/7 access
- To be listened to
- To be remembered and contacted after death

System EOL Collaborative

□ Core Values

- Education
- Early identification of patients appropriate for hospice care
- Advocacy
- Respect for personal preferences
- Staff Support

“Burning Questions”

- Why is hospice an under-utilized service?
- Are nurses comfortable approaching patients and families regarding hospice?
- From a nursing perspective, what would improve the quality of care for patients and families at the end of life?
- Do nurses feel comfortable talking with physicians regarding EOL care/hospice?
- Do nurses feel empowered to dialogue with physicians regarding futile treatment?
- Why are not more physicians proactive in EOL care?

Research Questions

- How do nurses characterize EOL/hospice care, communication and attitudes in their current work setting?
- How do nurses describe the level of moral distress in their current work setting?
- Do associations exist between these characterizations of EOL/hospice care, communication, attitudes and moral distress.

Methodology

- ❑ Design:

A descriptive study using a survey design and a convenience sample

- ❑ Setting:

The survey was distributed at Saint Barnabas Medical Center and Clara Maass Medical Center

- ❑ Time Period:

Surveys were distributed during an eight month period from 2012 to 2013

- ❑ Instruments:

- Hamric's (2012) Revised Moral Distress Scale; 21 items
- Boyd's (2011) Adapted version of Caring for Terminally Ill Patients Nurse Survey; 55 items

Conclusions of Research

- More discussions with patients and families were initiated by RNs trained in EOL/hospice.
- 53% reported difficulty talking with patients and families about dying.
- Frequently reported reasons for not discussing EOL/hospice were physician- related and family refusal to discuss.
- Nurses stated that physicians have difficulty talking about dying with patients and families.
- Nurses stated physicians are reluctant to tell patients they are dying.

Conclusions of Research

- Significantly higher levels of moral distress was found amongst RNs who felt the physician did not order enough pain medication for the terminally ill.
- Significantly higher levels of moral distress were associated with the statement “I never raise hospice unless the MD has discussed it already.”
- RNs described “witnessing the healthcare provider giving false hope” as most morally distressing.
- RNs stated they witnessed diminished patient care quality due to poor team communication with the physician.

Moral Courage Definitions

- Involves the willingness to speak out and do what is right in the face of forces that would lead a person to act in some other way
- Physical and/or emotional suffering that is experienced when internal or external constraints prevent a person from taking action that one believes in (Pendry 2007)

When do Nurses use Moral Courage

- When faced with a situation that poses a direct threat to patient care
- When faced with an ethical dilemma
- When faced with colleagues who are jeopardizing patient care
- When advocating for the wishes of a patient that are in conflict with the Physician /Family

Core Values of Moral Courage

- Honesty
- Respect
- Fairness
- Compassion

Strategies necessary for Moral Courage

Why C-O-D-E?

- C= Courage
- O=Obligation to Honor
- D=Danger Management
- E= Expression

(Lachman, Vicky (Sept 30, 2010) "Strategies Necessary for Moral Courage" The Online Journal of Issues in Nursing)

Courage

- Assess the situation
- Use affective and objective information
- Determine if moral courage is necessary

OBLIGATIONS

- Take a time out to reflect on your ethical obligations
- Determine what ethical values or ethical principles are at risk
- What's the right thing to do?
- What ethical principles need to be expressed or defended?

Danger Management

- Use cognitive approaches to manage your fear and risk aversion
- Explore possible actions and consider adverse consequences associated with those actions
- Need to focus on situation clearly
- Self soothing methods

Expressions

- Express your beliefs
- Take action thru assertiveness and negotiation skills
- Develop moral courage through education and practice

Barriers to Moral Courage

- Organizational culture
- Lack of concern by colleagues who don't have the moral courage to take action
- Group think
- Preference for redefining unethical actions as acceptable

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End of Life Communication

- One of the most difficult tasks a health care provider has to do
- Usually a devastating experience for patients
- Most patients want to know diagnosis and prognosis
- Strengthens physician-patient relationship
- Fosters collaboration
- Permits patients/families to plan and cope

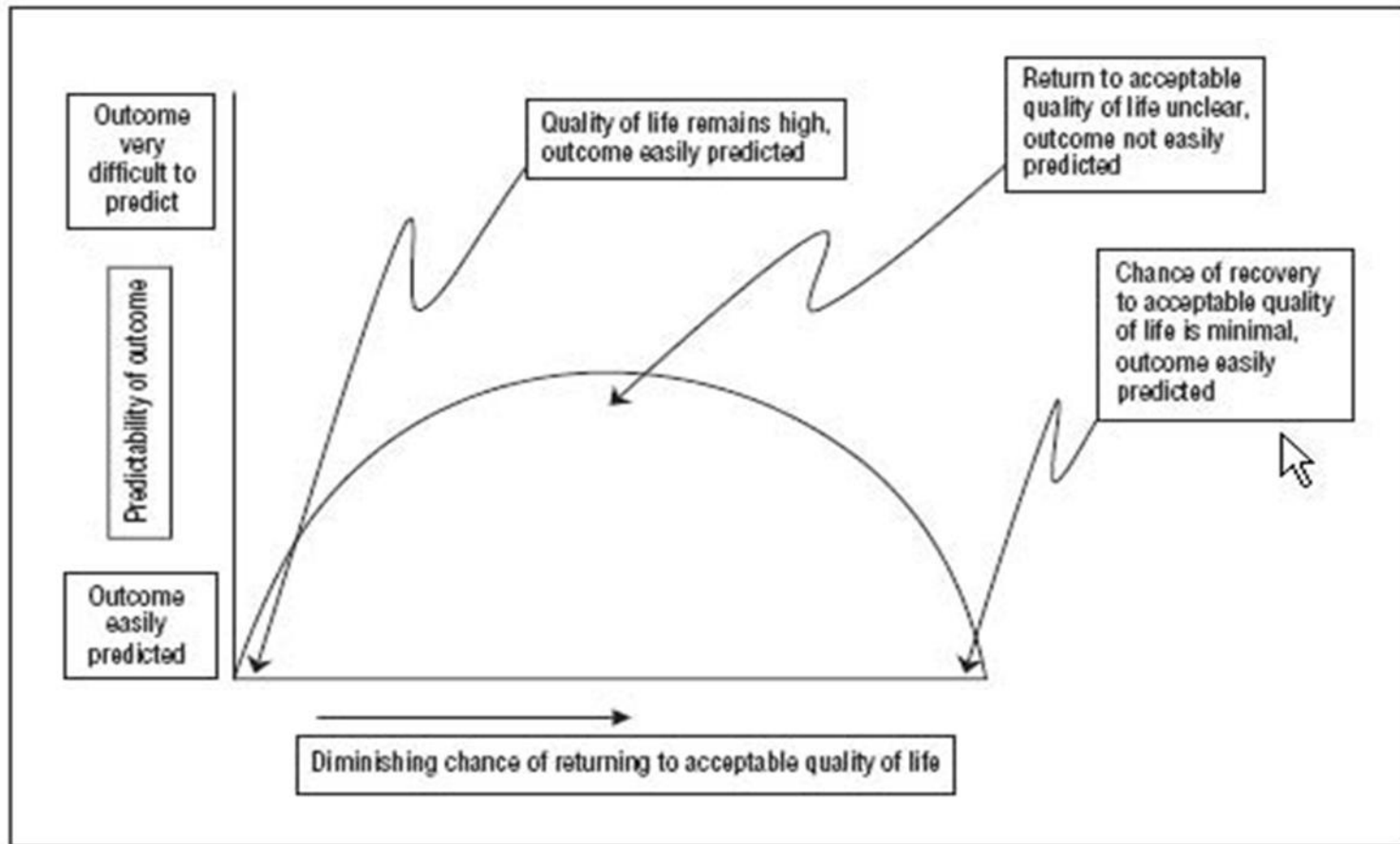


Figure. Conceptual model of the relationship between the ability to accurately predict outcome and the diminishing chance of returning to an acceptable quality of life. As illness progresses, the role of the physician changes across the entire continuum, but for the sake of clarity only 3 points are shown.

Conversation Starters

- What is your understanding of your illness?
- What are your expectations at this time?
- What is important to you?
- What are your fears and worries about what might happen?
- What would you want not to happen?

Communication

- Provides for informed choices
- Offers support
- Allows verbalization of fears
- Asserts control

Importance

- Most people want to know
- Strengthens clinician - patient relationship
- Fosters collaboration
- Permits patients and families to better plan and cope.

Communication Steps...

- Get started
- Determine what patient/family knows
- How much do they want to know?
- Share information
- Respond to patient/family reactions and feelings
- Plan and follow-up

. . . When family says “don’t tell”

- Ask the family:
- Why not tell?
- What are you afraid I will say?
- What are your previous experiences?
- Is there a personal, cultural, or religious context?
- Talk to the patient together

Giving Hope

- If we give false hope it may deflect from other important issues
- Redefine hope

Unrealistic Goals

- Wish/Hope-Worry/Concern
- Patient: I've had a bad week due to an infection (stage 4 lung cancer-progressing)
- Provider: I wish that your symptoms could all be explained by your recent cold, but my concern is that your cancer is not responding to the chemo and is causing more breathing difficulty
- Patient: I feel I have a good 5 years left
- Provider: I wish that were the case, but my worry is that your heart disease is worsening causing increased weakness and shortness of breath.

Language: Unintended Consequences

- Do you want us to do everything possible
- Will you agree to discontinue care
- It's time to talk about pulling back
- I think we should stop aggressive therapy
- There's nothing more I can do so I'm sending you to the Palliative Care Team

See the Difference

- Let's focus on aggressively treating your symptoms so we can improve your QOL
- I think the chemotherapy may be increasing your symptoms
- I'm going to focus on relieving suffering
- I'll do everything I can to help you maintain your independence
- I want to ensure that your father receives the kind of treatment he would want
- Your child's comfort and dignity will be my top priority

Supporting Patient's Goals

- Our team will focus on providing the support that you and your family desire
- Let's discuss what we can do to fulfill your wish to stay at home
- Let's discuss what we can do to get your child back home with supportive services
- You stated your goal was to be at home and not come back to the hospital. Hospice can provide the support to accomplish that goal

Language about palliative care that has more positive connotations

- I'm going to give the best care possible until the day you die.
- We will concentrate on improving the quality of your child's life.
- We want to help you live meaningfully in the time you have left.
- I'll do everything I can to help you maintain your independence.
- I want to ensure that your father receives the kind of treatment he wants.
- Your child's comfort and dignity will be my top priority.
- I will focus my efforts on treating your symptoms.
- Let's discuss what we can do to fulfill your wish to stay at home.
- Let's discuss what we can do to have your child die at home.

EOL Values Scale

- On a scale of 0-5, 0 meaning not at all important, 5 meaning extremely important
 - How important is/are:
 1. your religious or spiritual beliefs?
 2. your wish to have a dignified death?
 3. your wish to be spared pain?
 4. your wish to avoid burdening family and friends emotionally?
 5. your wish to avoid burdening others financially?
 6. your wish to avoid being dependent on others?
 7. the wishes of other family members regarding your care?
 8. your wish to live as long as possible?

Seven steps in negotiating goals of care

1. Create the right setting
2. Determine what the patient and family know
3. Explore what they are expecting or hoping for
4. Suggest realistic goals
5. Respond empathetically
6. Make a plan and follow through
7. Review and revise periodically, as appropriate

Pearls

- Non-judgment-we should care for our patients regardless of the choices they make. We may disagree with their choices, but it should not affect our care
- Non-resistance-when we sense resistance within ourselves, we need to pull back and let things play out
- Non-attachment-don't get attached to the outcome or you will feel a sense of failure. It is the patient's goals and wishes, not ours