Finding Strength at End of Life

Recognizing the impact of patient death on clinical caregivers

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Objectives

• Recognize the impact of patient death on you as a clinical caregiver
• Distinguish between the concepts of grief, bereavement and mourning.
• Know the importance of companioning others as they grieve.
• Identify positive self coping mechanisms for dealing with your own cumulative grief and loss.
DISCLOSURE

The content of this presentation does not relate to any product of a commercial entity; therefore, I have no relationships to report.
About me and my hospital

- Pastoral Care Coordinator at Primary Children’s
- Serving a five-state area; level 1 trauma; 280 plus beds
- Member of Family Support Services
- Child Life, Social Work, Interpretation, School etc..
- Manage approx 30 Spiritual Care Volunteers
- Different ages and religious backgrounds
- Cover the entire hospital
- Rounding and clinical visits
- Strong concern for staff
- Emotional and spiritual support
- About 200 deaths a year because of high acuity
- Mercifully, I don’t attend them all…
Some preliminary questions

• How many of you have been present when one of your own loved ones has died?
• How many of you have been present at the death of a patient?
• How many of you have experienced compassion fatigue at times?
• How many of you realize that grief can be a major contributor to burnout in medical staff?
Why we burn out

“We burn out, not because we don’t care, but because we don’t grieve...because we have allowed our hearts to become so filled with loss that we have no room left to care.”

Rachel Naomi Remen,
*Kitchen Table Wisdom*
1. The Impact of Death
What makes us human?

Living with the knowledge of our own death and the death of all our loved ones
Common caregiver comments…

• I’m doing OK
• I’ve learned not to let in bother me
• I’ve got to hold it together at work
• I do my falling apart at home
• I’ve been doing this for so long, nothing gets to me any more
KEEP CALM AND CARRY ON
How does patient death impact us?

- Sadness
- A sense of loss
- A sense of failure?
- A sense of powerlessness?
- A sense of responsibility?
Let’s talk about responsibility

Responsibility to others

vs.

Responsibility for others
When I feel responsibility for others

<table>
<thead>
<tr>
<th>I do</th>
<th>Fix, protect, rescue, control</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel</td>
<td>Tired, anxious, fearful, liable</td>
</tr>
<tr>
<td>I am concerned with</td>
<td>The solution, answers, being right</td>
</tr>
<tr>
<td>I am</td>
<td>A controller, assertive</td>
</tr>
<tr>
<td>I do</td>
<td>Show empathy, encourage, share, listen</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>I feel</td>
<td>Free, whole, congruent</td>
</tr>
<tr>
<td>I am concerned with</td>
<td>Relating person to person</td>
</tr>
<tr>
<td>I am</td>
<td>A guide, helper, facilitator</td>
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Even with good boundaries, we can feel...

- Overwhelmed by other people’s pain
- Unable to help them in so many ways
- Angry at injustice and ignorance
- Saddened at the end of a long shift
- Wondering “What good did I do today?”
The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.”

Rachel Naomi Remen
The real question...

How wet are your feet?
We are all affected by death

“…any man's death diminishes me, because I am involved in mankind. And therefore never send to know for whom the bell tolls; it tolls for thee.”

John Donne, 1624
“No Man Is An Island”
2. The Grieving Process
Some definitions

- Bereavement
- Grief
- Mourning
What is bereavement?

- From the archaic word “reave” – to take away by force
- A “reaver” was a thief – plunder valuables
- So, someone who is “bereft” or “bereaved” – has had something very precious taken away by force
What is grief?

- Kubler-Ross stages the mourner moves through over time to get over the death of their loved one and back to “normal” life? Denial, anger, bargaining, depression, acceptance.
- A roller coaster of ups and downs over which we have no control until the “ride” is over?
- A weakness that “emotionally strong” people avoid giving in to at all costs?
- A pathology? Removal of the “bereavement exclusion” for diagnosing Major Depressive Disorder in DSM-5 seems like an attempt to do this.
What is grief?

• “Grief is not an illness from which we recover. It is a life-changing event that happens to all of us.” Dr. Phyllis Silverman
• “Grief is the normal and natural response to the loss of someone or something important to you. It is a natural part of life.” NHPCO website
• My definition: “Grief is a condition of the soul that responds best to the compassionate presence of another human being.”
What is mourning?

- Mourning: the things we do to give grief a voice.
- Mourning rituals in modern American society?
- America 100 years ago…200 years ago?
- Other cultures or parts of the world today?
- Why do we not mourn our losses any more?

“America is the most mourning-avoidant culture on the planet today.” Alan Wolfelt
Re-definition: cause & effect

- Bereavement
- Grief
- Mourning

Bereavement: A violent loss
Grief: Natural emotions
Mourning: Reintegrating loss into life
Four tasks of grieving/mourning

- Task 1: Accept the reality of the loss
- Task II: Work through the pain of grief
- Task III: Adjust to the environment without the deceased
- Task IV: Reinvest in life while remembering the deceased

William Worden
Dual process model of grief

Loss-oriented
- grief work
- intrusion of grief
- breaking bonds/ties/relocation
- denial/avoidance of restoration changes

Restoration-oriented
- attending to life changes
- doing new things
- distraction from grief
- denial/avoidance of grief
- new roles/Identities/relationships

Everyday life experience

Stroebe and Schut, 1999
Humans are complex systems...
Loss causes systemic stress...
Spiritual distress

“Disruption in the life principle which pervades a person’s entire being and which integrates and transcends one’s biological and psychosocial nature.”

(NANDA North American Nursing Diagnosis Association)
Indicators of spiritual distress

- Trauma that shakes basic belief system
- Anger at God/Higher Power
- Loss of belief/trust in God/Higher Power
- Loss of trust in religion/faith group
- Feelings of helplessness & hopelessness
- Nothing to hold on to in the current crisis
- Looking for answers to “Why?” that medicine cannot provide
Spiritual wellbeing

“The ability to experience and integrate meaning and purpose in life through a person’s connectedness with self, others art, music, literature, nature, or a power greater than oneself.”

(NANDA)
The work of grief support

To help bereaved people move back towards spiritual wellbeing through our presence, listening, and compassion.
Cumulative losses cause cumulative stress...
As critical caregivers, we are all subject to cumulative stress and other people’s grief.
Vicarious grief

- Sorrow felt at another person’s loss
- When are you likely to experience vicarious grief in your work as a caregiver?
- Can you recognize cumulative vicarious grief?
How can you tell when your stress level has become too much - before things are overwhelming?

Some common signs that you need to slow down include:

- Impatience or edginess
- Lack of enjoyment
- Sleep problems
- Exhaustion
- Others?
Do you.....?

because

MAKE time
For YOURSELF

YOU
are IMPORTANT
3. Companioning Others in Grief
Re-definition: grief support

- Bereavement
- Grief
- Mourning

Presence, Listening, Compassion
Presence

• There is no greater gift one human being can give another than the simple gift of presence, given without agenda, judgment or expectation.

“Healing presence is the condition of being consciously and compassionately in the present moment with another or with others, believing in and affirming their potential for wholeness, wherever they are in life.”

James Miller, *The Art of Being a Healing Presence*
When we really listen to another person, we validate their emotions, experiences and situation.

“Healing listening has to do with being rather than with doing... When we listen in a healing way, we carry no agenda for the other person or for ourselves. We listen because we choose to listen, without knowing what will transpire... We listen because the other person is worth being listened to...”

James Miller, *The Art of Listening in a Healing Way*
Compassion

From the Latin words “com” = with & “pati” = suffer

• Empathy = understanding
• Sympathy = feeling concern
• Pity = feel sorry for

Compassion = feel emotions with
Companioning the mourner

- Acknowledging that grief forever changes or transforms the mourner’s world view

- Not about:
  - Assessing
  - Fixing
  - Changing

- Is about:
  - Being present
  - Listening
  - Being taught

- Letting the mourner give voice to grief
Ways to give voice to grief?

• How have you experienced people grieving?
• What is “normal” grief in your opinion?
• What have you seen as helpful/unhelpful?
• How do you grieve?
4. Positive Coping Mechanisms
“We burn out, not because we don’t care, but because we don’t grieve...because we have allowed our hearts to become so filled with loss that we have no room left to care.”

Rachel Naomi Remen, 
*Kitchen Table Wisdom*
Care for yourself as well as you care for others

Treat your heart as you would treat a new born baby, fragile and delicate.

Taking care of yourself is the best selfish thing you can do.

Sometimes ... I need to remind myself that taking time for me is not selfish but necessary.

Don't just be good to others. Be good to yourself too.
Our wishes

- We wish grief would resolve
- We wish it was linear and finite
- We wish we could wake up one day and our painful thoughts and feelings would be over
What griefs are you carrying?
The good news

“Mourning waits on invitation, not on time”

Alan Wolfelt
Personal loss timeline

What types of grief and loss have you experienced in life?
Rituals that recognize grief

• Mr. Rogers
  • Leave the coat and shoes in the hall closet

• Deliberate acts
  • Write a story
  • Light a candle
  • Float a paper boat down a stream
  • Plant a tree
  • Start a rock garden
Advice for healthy living

- Do not consider grief a weakness
- Don’t be among the hidden collateral damage
- Talk honestly to someone you trust
- Recognize that the griefs you carry contribute to stress
- Give voice to grief/relieve stress through rituals
- Develop a regular spiritual practice
Sea Glass

A metaphor for grief:

“Rich and strange like polished sea glass are the hard gems of grief created from the shattered fragments of our lives after time has rolled and tumbled them along. And as we pick them up, turn them over in our hands, wet them again, sometimes with the water of our tears, they sparkle and shine like precious jewels.”

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