It is never too late to assure “Good Grief” for your clients.

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RIDDNA

Missing at the college level

- IDD as a content area
- Educational preparation for end-of-life care

What’s happening?

ADNU / BSN
- Missing at college level: IDD as a full content area
- Educational preparation for end-of-life care
- CEU’s state and national groups
- Certification(s)

Masters / APRN
- Specialty class options
- More self directed degree options
- CEU’s state and national groups
- Certification(s)
• Steering Committee formed for the Palliative & Hospice Nursing Professional Issues.
  (20 members and more than 200 Advisory members – People are interested!
  \[\text{deliberations via twice monthly 2-hour telephone and internet-based meetings, supplemented with additional small group conference call activities, research and projects}\]

Content area Issues

- End of life, grief and loss is competing for placement in most curricula
- Absent for the complicated needs of the individual with IDD and end of life issues.
- End-of-life education in nursing schools is inconsistent.

Attention Needed

- Assure proper level of support during times of significant emotional difficulty (nurse, DSP etc.)
- Assure training, education and follow-up at all levels
- Embrace differences
- Appreciate
What are your wishes?

The capacity of the person with IDD to grieve

- Considered incapable of grief,
- Do not possess the necessary capacity to form meaningful relationships,
- To experience complex emotions
- Or the necessary understanding of death to experience loss or mourning

More:

- The capacity of the person with IDD: Do not underestimate.
- What is grief and how might it be compounded.
- What’s healthy and productive and how to express it.
Nursing:

Just like non-disabled individuals, our clients
- Experience a wide-range of emotional stress
- Before, during and after a loss and
- It is our responsibility to help them

Definition

Grief is an internal response to loss. With physical, behavioral, emotional, mental, social, and spiritual components.

Described by some as a heaviness that isn’t easily lifted. It can sometimes be so pronounced that it affects a person’s physical self and can even mimic illnesses.

Bereavement

Normal Grief

Bereavement
- The sense of loss following a death

Grief
- The powerful sorrow that an individual feels at the death of another

Mourning
- The ceremonies and behaviors that a religion or culture prescribes for people to employ in expressing their bereavement after a death
Typical Grief Indicators

- worry
- sadness
- weight
- head aches
- insomnia
- moodiness
- irritability
- tension
- crying
- memory
- muscle
- anger
- agitation
- mental
- stomach
- bowel

Typical Concept of Death
infancy - toddler years

- Child reacts to emotions of parent / people around them
- Grief of others permeates their environment
- Child may cling to adult, cry, have stomach upsets, vomit and or regress with toilet habits

Age three to five years

- Death is equated to sleep
- Death is measured: a little, kind of and real
- Children mostly live in the present w/ vague understanding.
- Children may regress to infantile behaviors, ask repeated questions, fear separation and or show little concern when told of the death.
Age six to nine years

- Have a clearer understanding of death.
- Begin to fear death and may equate a death with punishment.
- Realize death is final and it can happen to them.
- Children may show grief reactions, anxiety and unwillingness to discuss the death.

Age ten to twelve years

- Are curious about death.
- View death as final and inevitable.
- May feel somehow responsible for the death.
- These children may begin daydreaming, grades may fall off, may emotionally distance themselves, cannot understand why it wasn't fixed.

Teenagers

- Engage in risk-taking behaviors and may have feelings of immortality.
- Have more adult understanding of finality but are hopeful that the news in not true.
- Teenagers might assume an adult role with younger children, may attempt suicide, show aggression or become preoccupied with death.
Sources of Hope and Strength

- Who is the most important person to you? Why?
- To whom do you turn when you need help? Are they available? How do you ask?
- In what way do they help?
- What helps you the most when you feel afraid or need special help?

Categories of Loss

- Tangible – concrete (divorce, property, miscarriage, parts of oneself i.e. child, body part)
- Intangible – psychological (dreams, security, self-confidence)
- Men and women may deal DIFFERENTLY
- Loss is INDIVIDUAL
- Grief can be DELAYED

Factors that affect grief

- Developmental – age
- Religious – rituals, beliefs, prayer
- Cultural
- Relationship with deceased
- Cause of death – suicide, accident
- Perceptions – grief can be cumulative
- Anticipatory
- Psychological – problems effecting coping
Theories of Grieving Process
Dr. Elisabeth Kubler-Ross

• Denial
• Anger
• Bargaining
• Depression
• Acceptance

Research on Grief

- Mixed beliefs that adults with developmental disabilities experience grief and should be included in the process and rituals.

- Demonstrates that more still needs to be done in the area of grief and bereavement in this population.

- People with IDD are living longer and experiencing deaths around them.

Research continued

- People with developmental disabilities have been portrayed as unable to form bonds that produce feelings of loss.

- People with developmental disabilities have been protected from the rituals associated with death so as to not upset them or to induce stress which might lead to inappropriate behavior.
The dignity of choice.

Your / Our choice
• Is dying at home an option?
• What resources do we need / want when we are dying?
• What are our the wishes?

Most people with IDD
• What makes the most sense?
• Impact on others
• What is efficient, cost effective?
• Staffing costs / implications
• Resources, supports

You
Make a Difference

“You don’t have to see the whole staircase, just take the first step.”

Rev. Martin Luther King, Jr.
Take Care of You, so you can care for others

- Death affects everyone
- Take care of your health, body and nutrition
- Keep a journal
- Spend time with others
- Set limits
- Do things that make you feel good
- Have a routine
- Find beauty in nature
- Laugh

Be Aware of the Power of belief

- Know your client
- Know the families practice and traditions
- Have available materials
- Be honest
- Review
- Involve
- Be present
- Remember
Be aware of Funeral traditions & practices

The funeral is a time of reflection and joy, but also sadness, as the person will be missed by loved ones.

Believe that there is a heavenly afterlife and will then see God face to face.

If a person has committed a grave offence and has not repented at the time of death then that person would not enter into the full glory of heaven.

The Christian trusts they will go to heaven to be with God.

Catholic

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The Catholic believes that the soul moves from one body to the next on its path to reach Nirvana (Heaven). A sad time when someone dies, but is also a time of celebration.

Christian

Catholic

Jewish

Beliefs vary: Orthodox, Reform or Conservative.

Jews believe that when they die they will go to Heaven to be with God.

Death is seen as a part of life and a part of God’s plan.

Jewish

Hindu

Hindus believe in reincarnation.

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Hindu
**SEVENTH DAY ADVENTIST**

Seventh Day Adventists believe that death is an unconscious sleep. When Christ returns to the earth all will be awakened and those who believe in him will go to be with God in heaven.

**SIKH**

Sikhs believe in reincarnation. If a person lives their life according to God's plan then they can end the cycle of rebirth in this life. They believe in an afterlife where the soul meets God.

**BUDDHIST**

Buddhists believe in rebirth. The goal is to escape the cycle of death and rebirth and attain a state of perfect peace. There are lots of different types of Buddhism and many different ways of dealing with death.

**SCIENTOLOGIST**

Scientologists believe that humans are immortal spiritual beings who live several lives. Each has a body and a mind, which exists from lifetime to lifetime. When a person dies they simply move into a new life.

**MAORI**

Traditional Maori believe that the spirit continues to exist after death. The deceased will always be a part of the marae. Once someone has died they will go to the spirit world.

**JEHOVAH'S WITNESS**

Jehovah's Witnesses believe that when they die they go into a kind of sleep until God resurrects them from the dead. Those who gain entrance to heaven will live with God or the majority will be resurrected to a restored paradise on earth.
Muslims believe that the soul continues to exist after death and accept death as God's will. Muslims believe in judgment by Allah where Heaven or hell is the outcome. Until then the deceased remain in their graves.

CHURCH OF JESUS CHRIST LATTER DAY SAINTS

Church of Jesus Christ Latter Day Saints believe that at death the body and the spirit separate. The spirit goes to the spirit world before being reunited with the body following judgment day. The deceased will live in Heaven with God.

Strategies
- therapeutic communication
- let client set agenda for conversation
- avoid clichés
- give accurate and honest answers
- commemorate the loved one
- be present
- use silence effectively
- touch as appropriate
- be available
- make other available
Strategies continued

• behavioral rehearsals
• review of the sequence of events in relation to the specific religion and cultural rituals.
• if possible make client aware of emotions they may see from others and feel themselves
• provide bereavement day(s) from work to reflect, plan and shop
• utilize resources prepared in advance to use as guide.(Five Wishes, Celebrating Life etc.)

Strategies continued

• provide a grounding activity
• remind the person that he/ she is loved and well thought of
• be patient
• acts of kindness
• be prepared
• give choices
• Review stories
• Read coping books about loss, heaven, death etc.
More

- Teach and foster problem solving
- Promote self esteem
- Provide encouragement
- Provide direction
- Give permission for happiness
- Embrace tears
- Promote a group
- Get further help if needed
- Listen and watch for cues
A good death

- Adequate pain and symptom management.
- Avoiding a prolonged dying process.
- Clear communication about decisions by patient, family and physician.
- Adequate preparation for death, for both patient and loved ones.
- Feeling a sense of control.
- Finding a spiritual or emotional sense of completion.
- Affirming the patient as a unique and worthy person.
- Strengthening relationships with loved ones.
- Not being alone.
Prepare for Grief

- Include circles of life examples
- Use life legacies or personal wish lists
- Journals
- Reinforcement / interest surveys
- Teach emotions
- Teach positive psychology – gratitude, forgiveness, kindness, respect, honesty ..

Do not be afraid to share
Listen

Take time to look beyond the “behavior”.

Nick’s sister died 3 years ago, dad died unexpectedly 2 months ago. He yells, hits others and cries each afternoon at 2:30. His staff block the hits, stay with him and provide support. He is grieving.

Matter-of-fact capacity

“I shall be blunt. My father may be dying. He’s on full breathing machines and on so much medicine that he’s incapable of waking up. But even if it doesn’t get worse then this will be the end. This specific treatment will eventually cause damage to his body and a heart attack is possible. My father already decided that if his heart stops that it won’t be restarted. Writing this is painful.”
Other examples?

Henri Nouwen

“Beyond the Mirror” Henri’s personal reflections before his death he writes,

“I felt a deep desire to forgive and to be forgiven, to let go of all evaluations and opinions, and to be set free from the burden of judgments.”

Conclusion

Grief is a normal and universal experience among human beings.

The sorrow of loss is shared by all, including those with developmental disabilities.

As we have seen, people with developmental disabilities are able to understand the meaning, finality, and irreversibility of death, despite cognitive and developmental limitations.
Sharing ideas

THANK YOU