Helping Individuals Cope with Life-Threatening Illness and Grief

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The Role of Models

- Order from Chaos – The Value of Models
- Theory and Research
- The Limits of Models
  - Useful for Therapist
  - Useful for Client
Kübler-Ross

The Stages of Dying

- Denial
- Anger
- Bargaining
- Depression
- Acceptance and
- Hope
The Dominance of the Stage Model

- Early work in line with psychological models and medical staging
- Offered a way to medically manage dying so that the patient died accepting death.
- Kübler -Ross was very charismatic
- Klass “Kübler -Ross spoke of a romantic, natural death at a time when the “natural birth” movement signaled a revolt against a dehumanizing technology”
Kübler-Ross’ Work Had Great Value

- Historical and heuristic
- Reminder to communicate with the dying
- Yet, Corr reminds us there are lessons we should and should not learn from Kubler-Ross
The Reality of Death Is Now Different

- Living-Dying interval is longer
- Rando – “Most people today die suddenly from chronic illness.”
- Multiple diagnosis
- Much of life-threatening illness is lived beyond the hospital
- Philosophy is normalizing life
Criticism of the Stage Theory

- Little supporting research
- Descriptive or prescriptive
- Implied linearity
- Denial and acceptance are complex – middle knowledge
AREN'T YOU SUPPOSED TO BE DOING YOUR HOMEWORK?

I'VE PRETTY SURE THE ASSIGNMENT WAS OPTIONAL.

DENIAL SPRINGS ETERNAL.

IT'S NOT DENIAL. I'M JUST VERY SELECTIVE ABOUT THE REALITY I ACCEPT.
Shneidman’s Summation

- Dying patients are a “hive of affect”
- We can even make that a hive of reactions – not just affect but physical, behavioral, cognitive, and spiritual reaction
The Rise of Task and Phase Models
The Tasks of Grief

- Acknowledge the loss
- Express manifest and latent emotion
- Adjust to a changed life
- Relocate the loss
- Reconstitute faith and philosophical systems challenged by the loss

Worden (Modified)
The Value of a Task Model (Corr)

- Acknowledges that individuals face their own issues in their own way
- Non-linear
- Stresses individual autonomy – persons select tasks
- Counselor as facilitator
The Phases of Illness

- Prediagnostic Phase
- Acute or Diagnostic Phase
- Chronic Phase
- Recovery
- Terminal Phase
Tasks in Life-Threatening Illness

- Respond to the physical fact of disease
- Take steps to cope with the reality of disease
- Preserve self-concept and relationships with others
- Deal with affective and spiritual issues
Counseling Persons with Life-Threatening Illness

Six Key Issues

1. Counseling always takes place in the context of treatment goals
   - Possible Treatment Goals
     - Cure
     - Extend life
     - Palliative
   - Assumed goals are known and shared
   - Counselor as advocate
Counseling Persons with Life-Threatening Illness

2. Counseling is holistic
   - Person not patient
   - Life beyond Illness
   - Multifaceted Crises

3. Takes place in a context of open communication
Using Metaphors in Counseling

- Explore clients’ metaphors of loss
- For example – loss as a journey
  - *Where do you rest and get respite on a journey?*
  - *Are family members in the same place on this journey?*
  - *What is your destination? Where do you hope to go?*
The Terminal Phase

Tasks

1. Dealing with symptoms, pain, and incapacitation
2. Reducing stress and enhancing coping -- the immediacy of time for patients and survivors
3. Dealing with caregivers – personalizing the patient
4. Preparing for death and saying goodbye
The Terminal Phase

Tasks

5. Preserving self-concept in the face of death – including the importance of personal grooming (accepting dependence)

6. Preserving relationships with family and friends – empowering communication

7. Ventilating feelings and fears

8. Finding meaning in life
The Terminal Phase

*Spiritual Needs of the Dying Person*

- To live a meaningful life
- To die an appropriate death
- To continue beyond the grave
Modes of Symbolic Immortality

- Biological
- Creative
- Transcendental
- Theological
- Eternal Nature
- Medical
- Communal

(Lifton, modifications – Doka)
The Value of Reminiscence and Life Review

- Establishes time and role parity
- Bolsters self-esteem
- Establishes a continuity of identity
- As therapeutic tool
- Part of later life development
- Creates and bolsters community
Techniques for Life Review and Reminiscence

- Photographs and memorabilia
- Music and film
- Creative expressions
- Genealogies and genograms
- Reunions
- Pilgrimages
Use all senses

- Sound
- Sight
- Touch and texture
- Taste
- Smell and aromas
The Psychological Value of Leaving a Legacy

- How would you wish to be remembered by those around you?
- What are the stories you would wish they tell about you?
- What are the lessons you would wish that they take from your life?
Ethical Wills: A Tool for Legacies

“Legal wills bequeath *valuables*, ethical wills bequeath *values*.”
(Baines, 2002)
Living Eulogies

- An alternate approach to reinforce a sense of the meaning of life
- Family and friends are invited to a ritual to share their eulogies *prior* to the death
Innovative Interventions

- Breitbart’s *Meaning-Centered Therapy* builds on Frankl’s work by assisting cancer patients in finding meaning in a context of group support.
- *Dignity therapy* focuses on how patients wish to be remembered and the legacies they want to leave – Chochinov *et. al.* (2005) found this increased sense of meaning and purpose and enhanced a will to live.
Dignity Therapy Questions

- Tell me a little about your life history; particularly the parts that you either remember most, or think are the most important? When did you feel most alive?
- Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles you have played in life (family roles, vocational roles, community service roles, etc)? Why were they so important to you and what do you think you accomplished in those roles?
- What are your most important accomplishments, and what do you feel most proud of?
- Are there particular things that you feel still need to be said to your loved ones, or things that you would want to take the time to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]?
- Are there words or perhaps even instructions you would like to offer your family, to help prepare them for the future? In creating this permanent record, are there other things that you would like included?
New Innovations in Care of the Dying

- *Dignity Enhancement Therapy* (in clinical trials at Sloan-Kettering)
- Trained volunteers and staff record the life history of dying patients
- Within 24 hours the history is presented to the dying patient as a bound book and read to the patient and family
- The family retains the book
New Innovations in Care of the Dying

- *Doulas* were midwives
- Now *Doulas* are volunteers that assist as “midwives” for the dying – trying to help families and patients through the transition
- What would constitute a good death? What do you want to happen? Who would be around you?

(Fersko-Weiss)
New Innovations in Care of the Dying

Musical Thanatology

- Chalice of Hope
- Based on medieval manuscripts
- A prescriptive regimen of harp music tied to the body’s rhythms to slow to ease pulse and respiration and allow a good death
Musical Thanatology : An Evaluation

- Research found Vigils did lessen wakefulness and decrease agitation
- However there was no discernible effect on respiration despite prescriptiveness
  (Freeman, Caserta et al, 2006)
Communicating with a Comatose Resident

- Senses in a coma
- Monitor what is said, assume you are heard
- Reassurances
- Meaningful stimuli
- Ritual and prayer
- May offer an opportunity for family members to finish business – Context, their needs
The Tasks of Grief

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Worden (Modified)
The Assessment of Grief Interventions

Evidence-Based Practice
The Debate over the Efficacy of Grief Counseling

- In recent years, there has been a number of studies of the efficacy of grief interventions (Neimeyer, Currier, Larson & Hoyt, 2007; Allumbaugh & Hoyt, 1999)
- Collectively they remind us that grief interventions have to be based on careful assessment, individually tailored, and conducted by qualified counselors.
Effectiveness of Grief Counseling

- Grief counseling can be effective (Larson & Hoyt, 2007; Allumbaugh & Hoyt, 1999)
- Self-referral remains a key issue – “Reach but do not grab”
- Early interventions (3 – 4 months) seem to be associated with more positive outcomes
- Initial efforts might best involve psycho-education and strive to strengthen natural support systems
- Interventions should be based on models that see grief as a multi-faceted experience and understand the varied ways that persons cope with loss
Use Multiple Methods and Approaches

- There is no “silver” bullet – no set protocol or approach
- The individual nature of grief requires individualized treatment
- Be eclectic
- Be prescriptive
- Expressive approaches
- The value of an experimental ethos and evidence-based practice
The Value of Psycho-Education in Grief

- Essential role of validation
- Research on value of brief therapy and bibliotherapy
- Value of using psycho-educational programs along with other modalities
"...and last but not least, Dear Lord, take care of yourself. If you don't, we're all in trouble."
Caregivers Experience Multiple Losses

- Loss of a Patient
- Loss of a Relationship with Family
- Perhaps Personal Future or Past Losses
- Loss of Assumptive World
- Unmet Goals
- Death of Self
Papadatou’s Model of Caregiver Grief

Simultaneously experiencing and containing grief
Principles of Self-Care

- Individual
  - Validation
  - Respite and Stress Management
  - Philosophy
    - Role
    - Spirituality

- Organizational
  - Education
  - Support
  - Ritual
FRANK AND ERNEST

BEER 50¢

MY THERAPIST SAYS I SHOULD BE MY OWN BEST FRIEND, BUT I REFUSE TO LOWER MY STANDARDS THAT MUCH.

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The Needs of Dying Patients

*Dame C. Saunders*

- Stay with me
- Care for me
- Listen to me