Ethics and Working with Death, Dying, and Bereavement

Daniel J. Wachtel, Psy.D.
Clinical Psychologist
Geropsychologist
“I share the fear of death with every human being: it is our dark shadow from which we are never severed.”

Irvin D. Yalom, M.D.

https://www.youtube.com/watch?v=RrCQnRFBuGc&index=1&list=PLr8mtsv96OUim9kzryeZyRolbhhXoK15z
Death and Discomfort

Euphemisms for Death:
- Expired
- Passed
- Lost
- Moved on
- Not to mention the dozens that attempt to make light of death.

http://www.wingclips.com/movie-clips/patch-adams/death-quotes
https://www.youtube.com/watch?v=AR_oQvJKiCM
Death and Dying

- Woody Allen on Death:
  - “I’m not afraid of death, I just don’t want to be there when it happens.”
The Good News:

- Although the discomfort is natural and ingrained in our society, this is a skill. We can learn to do it, and do it well, but it takes the willingness to challenge yourself, face your fears, and anticipate your challenges.

- Take on this challenge, at least, for the next few hours.
Group Exercise

Imagine for a moment that you have just been informed that you have 24 hours to live.

- What would you do?
- Who would you spend those hours with?
- What do you regret?
- What are some of your thoughts and feelings?
Death and Dying

How do you know if you are able to, or not able to, do this type of work?
Questions to consider during this workshop

- How does the idea of doing this type of work make me feel?
- What do I do when I experience the death of a loved one while doing this type of work?
- What are some of my biggest concerns about working with death, dying, and bereavement?
Death & Dying

Why “Death, Dying, and Bereavement?”

Three parts to this presentation:

1) Treating clients who are grieving
2) Treating clients who are terminally ill/dying
3) What to do when a client has died
Death and Dying

Part 1:
Grief and Bereavement: Treating those that are mourning the death of a loved one.
Grief

- **Bereavement** - the experience of losing to death a person to whom one is attached.
- **Grief** - refers to the emotional distress associated with the experience of bereavement.
- **Mourning** - the social expression of grief or bereavement, and is often influenced by religious beliefs and cultural customs.
Grief

Grief: Is it a mental disorder?
Grief

- **How to differentiate experiences:** normal vs. diagnostic, complicated vs. uncomplicated, successful vs. problematic mourning.

- **Diagnostic terms:** traumatic grief, complicated grief, pathologic grief, abnormal grief, chronic grief, pathologic mourning.
History of Diagnoses

**DSM-IV-TR:**

**V62.82 Bereavement:**
- When the focus of clinical attention is a reaction to the death of a loved one.
- DSM-IV-TR referred to this V-code as “normal” grief.

**Criteria E for Major Depressive Episode:**

“…after the loss of a loved one the symptoms persist for longer than 2 months…” (rather than the typical 2 weeks)
Major gap in DSM IV-TR

- The 2 month window only applies to death, and not other major life stressor.
  - So, a person who experienced a divorce, disability, illness, or other life stressor would meet criteria, but person grieving would not.
  - “That’s like saying that just because the bereaved is more at risk for heart disease, a physician would write off chest pain as bereavement rather than a medical condition requiring further work-up.”

- DSM-5 eliminated the grief exclusion criterion from MDD.
Bereavement and grief in the DSM-5.

- Initial proposals for Complicated Grief were rejected.
- The grief exclusion criteria for MDD was eliminated. But, a long paragraph, in very small font, was added to MDD.
- The side note attempts to differentiate MDD from grief with the following:
  - Grief has focus on the deceased vs. all encompassing, does not include self-esteem issues, suicidal thoughts linked to joining the deceased not worthlessness.
Bereavement and grief in the DSM-5

- Only addition in DSM-5 is in section for “further research”

- **Persistent Complex Bereavement-Related Disorder:**

  - Criteria includes a list of symptoms that have persisted for min of 12mths.
  - Can add specifier “with traumatic bereavement” (homicide or suicide)
  - Differential DX: normal grief, depressive d/o, PTSD, and separation anx d/o.
Bereavement and grief in the DSM-5

- Differentiating Persistent Complex Bereavement Disorder with PTSD
- Can dx both
- Intrusive thoughts in PTSD focus on event, bereavement focus on relationship with deceased
- A focus on the manner of death and what happened.
- “A preoccupation with the loss and yearning for the deceased, which is absent in PTSD”
Grief- Prevalence

- 80%-90% of bereaved individuals experience normal or uncomplicated grief.

- **How to Conceptualize Bereavement:**
  It can be seen as a risk factor for the development of mental disorders.
  - We can expect to see an increase in symptoms (depression, anxiety, cognitive deficits, etc.) but not the development of a disorder.

Servaty-Seib, Zhang, et al. 2006
Clinical Scenario:

You are working in the geriatric department in a hospital and the program director approaches you and says, we need to offer bereavement services to our patients. You are asked the following:

- How do we determine who needs grief counseling?
- What questions would you ask a patient who recently experienced the loss of a loved one to assess how they are coping with that loss?
How long should one grieve?

- Grief, which can last weeks, months, or years, is a normal phenomenon that is healthy and adaptive.
- It’s not about the time/duration, it’s about the severity and the impact in one’s life.

Zisook, S. & Shuchter, S.R.
Grief

- Why talk about different types of grief in an ethics workshop?

- Well, the question is: do we treat, or recommend treatment for, something that may be normal, healthy, and adaptive?
Ethics Code 3.04 (APA)
Do No Harm

Risk of Treating:

 “The majority of bereaved people have no pathological indicators and do not usually require the help of professional counselors or therapists”.

 “Grief counseling is at best weakly effective and at worst harmful.”

Larson & Hoyt.; Bonanno & Lilienfield
Grief

- There is just as much empirical evidence that treatment works (Haley et. Al.)

- Risks of not treating:
  - Complicated grief Disorder symptoms have been associated with:
    - Increased risk of cancer
    - Hypertension
    - Cardiac event
    - Suicidal ideation
    - Functional impairment (social, family, work)
    - Increase alcohol and cigarette consumption
    - Increased rate of hospitalization
    - Reduced quality of life

Zhang, et al.
Grief

How to Assess true need:

- Does the client meet diagnostic criteria. (see handout)
- Look for functional impairment such as impairment in activities of daily living (ADL)
- **Two Screening Questions:**
  - 1) Are you having trouble dealing with the death?
  - 2) Are you interested in seeing a grief counselor to help with that?
Grief

Assessment instruments:

- The Hogan Grief Reaction Checklist (HGRC)
- The Impact of Event Scale-Revised (IES-R)
- The Texas Revised Inventory of Grief (TRIG)
- The Traumatic Grief Evaluation of Response to Loss
- The Inventory of Complicated Grief (ICG)
Grief

- So, now we have some skills, some knowledge, but all the information in the world is not going to matter if we can’t get it across.
- Bereavement counseling impacts the clinician in at least three ways:
  1) Awareness of losses
  2) Feared losses
  3) Existential anxiety

Dunphey & Schniering
Grief

- Counselors who treat clients experiencing grief also experience intense emotional and mental states.

- “How can we tread the thin line between empathy and over-identification with the client’s loss?”

Dunphy & Schniering
How to keep our balance:

- **Remember our role:**
  - **We help facilitate our client’s grief.**
    - 1) Know our own grieving process
    - 2) Appropriate use of self
  - **We help them with readiness for change:**
    - What in your grief expression is limiting your life?
How do we make the shift from viewing a personal loss experience as an interfering factor, to seeing it as a critical resource in our work with the patient?
Happiness after loss?

“What was now making her happy, she told me, was that finally, at the age of eighty in a retirement home, she had a room of her own...Letting her furniture go was a great loss, but also a relief. Leaving them felt like shedding a cocoon; freed from the ghosts of debris of the past, she had a new room, a new skin, a new start. A new life at the age of eighty.”

Yalom
How we can help:

- “...a potential awakening experience lies in almost every course of grief.”

- “Awakening consciousness can often be facilitated by the help of...a therapist with a greater sensibility to these issues.”

- **Human connectedness:** it is the synergy between ideas and intimate connection with other people that is most effective both in diminishing death anxiety and in harnessing the awakening experience to effect personal change.

Yalom
Group Exercise:

- You just experienced a death of a loved one and a long-time client of yours reveals that her husband just died and needs your help.

1) Do you agree to work with her?
2) If you do, do you share that you just lost a loved one?
3) How do you do this work, given your state of grief?
Death and Dying

**Part 2:**
Treating the Dying
Treating the Dying

Elisabeth Kubler-Ross’s 5 Stages of Grief:

Denial, Anger, Bargaining, Depression, and Acceptance.

http://www.youtube.com/watch?v=s6mh8SXs

https://www.youtube.com/watch?v=rW2SwoS3bks&index=5&list=PLr8mtsv96OUim9kzryeZYRolbhhXoK15z
Treating the Dying

Working outside of the box:

- Elisabeth Kubler-Ross eventually came to regret her 5 stages of grief. She felt that clinicians became overly focused on the stages and lost sight of what was most important, the dying person.
- Theory, research, and data are valuable, but don’t lose sight of what is most important.
Imagine yourself as the clinician in this video, what are your fears and what challenges does this type of work pose for you?

http://www.youtube.com/watch?v=tlZ97OALEfE&feature=related
Treating the Dying

- **Palliative Care** - the management of the physical, psychological, social, spiritual, and existential needs of individuals with advanced disease without reference to a specified life expectancy. Focused on treatment of conditions that are life limiting or refractory to disease-modifying treatment.

- **Hospice Care** - comprehensive palliative care provided during the last 6 months of life.
Treating the Dying

- A longtime patient with a terminal illness has been declining and reveals that they have made the decision to stop eating and drinking.
- What does this bring up for you?
- What do you say to your client?
- How does this guide your treatment plan?
- What do you say to their wife that wants you to “fix it”?
- Could a decision to end one’s life ever be rational and/or logical?
In June of 1997, the Supreme Court held that assisted suicide is not a constitutionally protected right and that its legality is left up to the states.

Physician assisted dying is currently legal in Oregon, Vermont, Washington, and Montana.

GA Law: Illegal and punishment is 1-10 years imprisonment.

See handout:

- APA does not advocate for or against assisted suicide.
- A psychologist does not have an obligation to break confidentiality when a client wants to hasten death in any way, including assisted suicide.
- “The psychologist’s role...is to protect client’s rights...not allow the affixation of a mental illness diagnosis if it is inappropriate, and help evaluate whether or not the client has decision-making capacity.” Werth et. al.
Treating the Dying

- What are the ethical dilemmas related to physician assisted suicide?
Treating the Dying

How can we rule out some of the ethical dilemmas?

- **Assessment:** Capacity, Depression, Mental Status, etc.
- Process topic and thought process thoroughly: “…frank and empathic discussion of the possibility of ending one’s life rather than facing ongoing suffering may actually reduce the risk of suicide.”

Goldblum & Martin
Ethics Code 3.04 (APA)  
Boundaries of Competence

To competently assist client’s in death, dying, and bereavement we must strike a balance between overreacting and under-reacting.

Three factors that influence balance:

1) Experience: more exposure = more comfort.
2) Clouded judgment: emotional reactions.
3) Lack of Training.
Clinical Scenario:  
(see Word document)

Ethical Considerations:

1) What we say may directly impact the client, their mother, and medical decisions made.

2) What role can we play, as health care professionals, in such an immensely complicated health care scenario?
“Not talking about death with a dying patient is like not talking about birth with a pregnant woman.”

Threadgill
Treating the Dying

- How can we help our patients with such medical decisions?

  - We can help them with their feelings, making sense of a diagnosis, communicating treatment preferences to their other medical providers and family.

Haley et.al.
Treating the Dying

- “It is only in the face of death that a man’s self is born.” St. Augustine

- “Confronting death allows us, not to open some noisome Pandora’s box, but to reenter life in a richer, more compassionate manner.” Yalom
Treating the Dying

"Death is on it's own clock"

Ren McCormack, Footloose 2011
How to assist the dying?

“What precisely do you fear about death?”

Goal of the question: to address the positive correlation between the fear of death and the sense of unlived life.
Addressing Fears (ours and theirs)

- Quote from a client’s eulogy for her mother: “Look for her among her friends.”

- **Rippling**: each of us creates concentric circles of influence that may affect others for years, even generations.
  - Rippling tempers the pain of transiency by reminding us that something of each of us persists even though it may be unknown or imperceptible to us.
How do we hold on to hope for clients who have lost theirs:

“No positive change can occur in your life as long as you cling to the thought that the reason for your not living well lies outside yourself. As long as you place responsibility entirely on others who treat you unfairly…bad genes…than your situation will remain at an impasse. You and you alone are responsible for the crucial aspects of your life situation, and only you have the power to change it. And even if you face overwhelming external restraints, you still have the freedom and the choice of adopting various attitudes towards those restraints.”

There may not be hope for recovery, but there is hope for finding meaning in life. — Yalom
Treating the Dying

Loss of Meaning and Need for Purpose in Life:

• What did Elisabeth Kubler-Ross say in the video about meaning?
• What meaning and purpose can a person have while bed-bound and dying?
Importance of Relationships:

- How can a dying client make change and enhance their interpersonal connections?
- Unfortunately, the dying person generally needs to take the lead in discussing fears about death with friends and loved ones.
  - Suggestion: “I notice you don’t respond directly when I discuss my fears. It will help me if I can speak openly to close friends like you. Is it too much, too painful, for you?”

Yalom
How we can help:

- Connection is most vital: Dr. Kubler-Ross realized this, and was why she most regretted stages.
  - Her plea was that we spend less time researching stages and more with the client.
- Get close in any way that feels appropriate.
  - Speak from your heart.
  - Reveal your own fears.
  - Improvise.
  - Hold the suffering one in any way that gives comfort.  

Kubler-Ross; Yalom
How we can help:

- Question for dying patient:
  - What can you do in your life, so that one year from now, you won’t look back and have similar dismay about the new regrets you’ve accumulated?

Yalom
Clinical Scenario:

A client of yours just learned that her husband has been diagnosed with terminal cancer, but he has not been informed of his condition. She would like to know whether she should tell her husband about his diagnosis.
Treating the Dying

- **Ask yourself:** Is hesitation to talk to pt. due to own discomfort, or is pt. not ready?
- **Listen:** for cues from the patient to determine the patient’s willingness to face the reality.
  - The more people in the patient’s environment who know of a terminal diagnosis, the sooner the pt. will learn anyway.
Treating the Dying

What about religion?

- For those of us who do not specialize in spiritual/religious counseling, how do we respond to religious issues, beliefs, and dilemmas?
- What do you say when their view of death, and what happens, dramatically differs from yours?
Treating the Dying

- Irvin Yalom, M.D., a self proclaimed atheist, said: “I cannot imagine attempting to undermine any belief system that is serving a person well, even a belief system that appears entirely fantastical to me.”

- “Thus, when persons with religious faith seeks my help, I never challenge their core belief…I often search for ways to support their belief.”
Death and Dying

Part 3:
When a Client Dies
When a Client Dies

- Multiple studies investigated the effects on clinicians treating dying patients and found that the clinicians, themselves, become bereaved following the death of a patient.

Dunphy & Schniering
When a Client Dies

- Death, and its finality, brings the central paradox of the clinical relationship, the therapists knowing a patient so intimately and yet being totally outside the social structure of that person’s life.
A reaction to the sudden, and unexpected, death of a client of many years:

“When they died, I was left with an enormous residue of personal grief, but without any formalized way to express it or a satisfactory connection to the usual mourning process. I couldn’t comfortably visit their families’ homes; I couldn’t discuss them with other people; I was an outsider at the funerals. My sadness, though private, was profound.

Rubel
Think of a client you are fond of and have been working with for a significant period of time. Imagine that they casually mention that they are having some new health problems. A few days after your next appointment you learn that your client died and the funeral is tomorrow.
When a Client Dies

- Should we attend a client’s funeral?
- What are some of the ethical dilemmas about attending?
- What are some of the questions we should ask ourselves prior to making the decision to attend a client’s funeral?
When a Client Dies

- What happens to the confidentiality records of a client who dies?
When a Client Dies

- This topic first reached public debate in the 90’s when Pulitzer Prize winning poet, Anne Sexton, gave permission to her psychiatrist to release her therapy tapes to her legal executor who later published them as part of a written biography.

Werth et. al.
When a Client Dies

- **Ethics Code 3.04 Avoiding Harm**
  - It has been argued that although not harming the deceased client, releasing records may be harming the publics’ trust in the mental health workers and their confidentiality. It may dissuade others from engaging in therapy.

- **Ethics Code 4.04 Minimizing Intrusions on Privacy:** include “only information germane to the purpose for which the communication is made.”
  - Document carefully, as records may be requested after death.
**Ethics Code 4.02 Discussing the limits of confidentiality:**

- Records may be released after death.

**Ethical questions:**

- When and how do we talk to clients about this?
- What to do when records are requested after a client’s death?
Ethics Code 4.02 Discussing the limits of confidentiality:

“You need to know before you disclose anything to me that, following your death, the executor of your estate may be legally able to obtain information and materials accumulated in the course of this psychotherapy. You and I need to discuss how you would like to proceed regarding highly sensitive material. In addition, you may want to consult with an attorney to request that these materials continue to be confidential following your death.”

Werth et. al.
Ethical Principle: Social workers respect the inherent dignity and worth of the person.

- Social workers are cognizant of their dual responsibility to clients and to the broader society.
When a Client Dies

How do you deal with, not just the death of one client, but repeated loss of many clients?
Elisabeth Kubler-Ross on how she personally dealt with the repeated loss of so many patients:

“I have so many good and wonderful and sometimes unique experiences with my dying patients. We go together through the stages and reach the stage of acceptance together. When the patient dies, I often feel good about it because he is relieved of his suffering and is at peace. Thus I feel I have done the best I could while he was alive. I then have to be able to wean off, to separate myself from this relationship and make my energy available to another patient. I think the art is not how not to get involved, but how to get deeply involved and be able to “switch gears again.” I feel sad when they die, but not depressed.”
When a Client Dies

Papadatou (2000) suggested a Model of the grieving process when a client dies.

- We tend to fluctuate between experiencing grief and avoiding grief.

  **2 part model:**
  - 1) Meaning making, or making sense of death
  - 2) Death transcendence and recognizing that you are finite and vulnerable in the face of death, and focusing on life.

Dunphy & Schniering
Just how challenging is this type of work?

When asked about pursuing a career in working with terminally ill patients, Elisabeth Kubler-Ross, M.D. said:

“I do not believe that anyone should work exclusively with dying patients five days a week, or nine hours a day. This work is extremely exhausting and emotionally draining. Each of us has to find his own way of “recharging the battery” before we are too drained and unable to give of ourselves.”
Death and Dying

- Don’t forget about yourself.
  - Work on a team, consultation group, or other form of support.
  - Attend to the impact of this type of work to you and your well-being.
  - Reflect on personal experiences of loss and it’s impact on your work and vice versa.
  - Attend to your own need to mourn and seek assistance when needed.
Resources

- APA Working Group on Assisted Suicide and End-of-Life Decisions
- Articles written by experts on end-of-life topics (www.findingourway.net)
- Veteran Affairs (VA) Bereavement Counseling (http://www.vetcenter.va.gov/Bereavement_Counseling.asp)
- Shivaconnect.com
- Elisabeth Kubler-Ross Foundation: http://www.ekrfoundation.org/
References

- American Psychological Association (APA) Ethical Principles of Psychologists and Code of conduct.


Smth, H.I. Coping with Grief: Clinical Interventions for Normal & Complicated Grief, Lecture.

Threadgill, B. End of Life Care. Texas Tech University Health Science Center Health.EDU.


