

**NHPCO Bereavement Section Chat-
Anticipatory Grief
2-1-2012**

Topic Clarification/Definitions

Eliot called this response *Pre-Bereavement*; Kulber-Ross termed it *Preparatory Grief*; while Hodgson and Krahn utilized the term *Early Grief*. Today the most familiar term is *Anticipatory Grief* and much has been written about what it is and what it isn't.

History of Anticipatory Grief (Handbook of Thanatology, p.23, 137-139)

- Lindermann (1944) grief reactions could be in anticipation of loss
- Fulton (1971 & 1980) term easily misused based upon assumption that acknowledgement and processing grief prior to loss would mitigate grief experienced after the death
- Rando-A. Grief a misnomer, but still useful term. Changed to A. Mourning. A. Grief refers to a reaction, while A. mourning is more inclusive (reactions and intrapsychic process that one uses to adapt to and cope with life-limiting illness. Future loss as well as current losses

NHPCO Guidelines & Medicare COP

Assessment begins with the pt admission to the hospice program and continues throughout the period of pt care and through bereavement support provided by the hospice after the death. Assessment includes individual risk for developing grief complications as well areas of strength that increase ability to cope. Assessment provides info for developing IDT POC. POC determines scope and frequency of team interventions. Bereavement professionals generally have contact with the survivor prior to completing post-death assessment in order to gather current info. POC updated as needed during additional contact. Assessment includes physical, emotional, social, spiritual, economic and intrapersonal strengths and weaknesses. (p.6, Assessment)

Definition

Anticipatory grief has been defined as the grieving process that commences when we learn of a loved one's life-threatening or terminal illness. The grief experienced before a death does not make the grief after the death last a shorter amount of time.

Some of the causes of anticipatory grief are related to fears and actual or possible losses, such as:

- Loss of social life
- Loss of companionship
- Loss of usual eating, sleep, work, and recreational habits
- Loss of independence
- Loss of control, such as, being able to care for yourself or a loved one
- Fears related to life without your loved one
- Fear of losing present family structure, such as head of household, the family matriarch, or frequency of visits from family members
- Fear of starting over
- Fear of the unknown

What are the different parts of anticipatory grief?

Anticipatory grief may include the following parts, though not exclusively in this order. Grief is often an expression which includes many of these components in multiple times, intensities, and orders.

- Individuals realize that death is inevitable and there is no expectation for a cure. Sadness and depression are often associated with this part of Anticipatory Grief.
- The next element of anticipatory grief is concern for the dying person. Sometimes family members experience regrets over past behaviors.
- The physical process of death and what may happen after death are concerns in this phase and the actual death may be "rehearsed." Funeral arrangements and saying good-bye to loved ones may occur as a result of some anticipatory grieving.
- Loved ones may imagine what their lives are going to be like without the person who is dying.
- People are able to complete "unfinished business" with the dying person (for example, saying "good-bye," "I love you," or "I forgive you").
- Sometimes it may feel that the grief process will not end as you experience loss.

Questions/Thoughts for discussion

- What are some common practices/considerations for providing education re: anticipatory grief (mourning) to families, community and staff?
 - In-services to staff re: anticipatory grief and risk factors.
 - One specific question to ask staff: "how might this behavior be a grief reaction"
 - Bereavement staff providing consultation to families in which it is anticipated that there will be complicated grief.
 - Referrals to bereavement when some of the following factors are present: concurrent risk factors; pt. is actively dying; present difficulty in coping/grieving; short length of stay on hospice.
 - Clients attempting to create relationships with you outside of the professional relationship.
- T. Rando, PhD's anticipatory mourning and its complexities based on:
 - Characteristics in relationship to the meaning of loss
 - Characteristics of the mourners
 - Characteristics of the illness and type of loss(es)

There were several threads of discussion regarding the above characteristics. Primary in the discussion was the assessment of these characteristics and by whom (which discipline). Primarily, the social worker and chaplains are responsible for the in-depth bereavement assessment, though all disciplines are charged with assessment from their scope of practice.

Another discussion revolved the providing information to staff around expected or "normal" grief reactions and maladaptive functioning. These range from information given at IDT to creating intranet in-services. One theme was

specifically around bereavement staff providing education specifically to social workers and chaplains who are charged with the on-going assessment of the patient and their families/caregivers.

A discussion was held regarding the EMR or assessment tool used to conduct the initial bereavement assessment. EMRs mentioned were consolo and allscript.

A discussion was held on smaller communities in which the counselor knows (& vice versa) the bereaved due to church, social, work situations. One person put it very nicely in that they always give the person the opportunity to “turn them down” as the counselor and if they accept then explicitly discussing confidentiality and boundaries. One person disclosed that a very good friend had her mother on the hospice program and would ask her to “check on her mother” outside of work situations and how difficult it was to attempt to maintain professional boundaries with a friend.

One particular discussion was around how anticipatory grieving can actually be a healthy function in that it is evident that a person is coping with present change/loss and is not in denial.

One discussion centered on providing community support for anticipatory grief. This community discussion included hospital and palliative care patients.

One discussion around: Hospice Disease Types Which Indicate a Greater Need for Bereavement Counseling by Brian W. Jones, American Journal of Hospice & Palliative Medicine. October 16, 2009. Is there a correlation between certain disease types and increased need for bereavement services? 3 diseases that consistently and more than 50% of survivors requesting additional services: lung cancer, Alzheimer's and renal failure.