



Anticipatory Grief



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Many of us are aware that grief is a normal part of every loss we experience, but does grief only occur after the loss? The purpose of this module is to increase the reader's awareness of the concept of anticipatory grief. There can be great benefits for both the person with dementia and their loved ones when anticipatory grief is identified and then addressed. For many, losses are not initially recognized at a cognitive level as grief, but are experienced at an emotional level through anxiety, sadness and depression. Increasing one's awareness of anticipatory grief will not only help to identify this feeling, but also provide interventions which may make one's journey a little easier.

Objectives:

- 1. Define anticipatory grief**
- 2. Describe factors that would influence anticipatory grief**
- 3. List ways to address anticipatory grief issue**

How would we define Anticipatory Grief?

The term anticipatory grief can have several meanings. It may have a specific focus (the impending death of an individual) and be more inclusive of secondary losses. It may be expanded to include illnesses like dementia where the person with the disease and their family are experiencing losses over a period of time. There may not necessarily be a terminal diagnosis.

The definition that is used in this context is as follows: ***Anticipatory grief is the form of grief that occurs when one is confronted with a chronic or life threatening illness or when one anticipates the death of a loved one (or oneself).***

Anticipatory grief is not a device for completing the tasks of grief prior to the death of the individual. Anticipatory grief does not substitute, or necessarily lessen, the post-death process. It is not post-death grief pushed ahead in time.

Who experiences anticipatory grief?

Anticipatory grief is experienced by two separate and distinct groups of individuals. With dementia, the two groups are the individuals with memory loss and those who care about them. Each group experiences anticipatory grief from their own unique frame of reference.

What is considered a loss?

Many times when we think of a loss we think about the death of a person. Now take a moment and look through the following sample list of losses that can be experienced by a person with a chronic or terminal illness. Reflect on each loss, on how it might affect you or some one you cared about. You may identify other losses as you read these.

Hope	Relationship	Truths	Desire
Joy	Community	Self-esteem	Purpose
Faith	Support	Balance	Patterns
Beliefs	"the Stories"	Memories	Freedom
Dreams	Security	Motivation	"Tomorrow"
Control	Time	Self Respect	Spirit
Goals	Physical ability	Inspiration	"Happy"
Roots	Inner Peace	Laughter	Balance
Expectations	Health	Energy	Intimacy
Work	Childhood	Harmony	Food

Past, present and future losses

Anticipatory grief is not limited to future losses, but it also includes past and present losses.

Past – the past that was had/shared and can never be regained.

Present – the losses that occur and are experienced as a decline in or out right end of capabilities, the ongoing experience of things slowly getting worse.

Future – the losses of the anticipated progression of the illness and such related losses as loneliness and events that will not be shared.

Here are some examples:

Past Lost

Sarah was in her seventies. She was the last living member of her family. She was still living independently, but this would not be for long for her cancer was progressing and her memory failing. She had good days and bad. One afternoon, her case manager stopped by. Sarah wasn't the friendliest person to be around. Today Sarah was sitting on the sofa and appeared to be very sad. She was holding on to what appeared to be a very old knitted bootie. When the case manager asked about it, Sarah, with a tear in her eye replied that this was her son's. According to the intake, there were not any children. Sarah told her case manager that over fifty years ago she had a son. When he was

four, he had been very sick and to administer his medication, she had to smash his pills into a powder so he could swallow them. One day she had smashed his pill and when she gave it to him, he aspirated and died. As was her family's custom, they had the funeral and afterward did not talk about the deceased. The grief of her son's death has been carried with her in silence. The loss she experienced in her past is now affecting the anticipatory feelings she has related to her impending death.

Present Loss

Mike had always loved fixing and restoring cars. This brought him much pleasure, sense of fulfillment, and praise from others. He had the knowledge and the skills to turn a Junker into a jewel. Mike found a beat up 1964 Ford Mustang, a car that was introduced when he was a teenager but could not afford. But now his life dream would come true. He purchased the car and started that labor of love in restoring old vehicle. He had been working on this car for years and was down to the last quarter panel. Now unfortunately, his loss due to his current illness had progressed to the point where he could not safely handle power equipment or be exact in the process of painting. He would easily become angry or upset as he stared at the unfinished "love" in the garage.

Future Loss

"When I retire or maybe when all of the kids are finally out of the house, we are going to buy a Winnebago and travel the country." Hours have been spent talking and planning for this time. Then the chronic or terminal illness hits and progresses. Not only are there the physical and cognitive losses that are constantly happening, but there are also the losses of dreams and expectations. All those hours watching the travel channel together, driving by the RV dealers, and plotting the trip are fading away. He can barely walk to the living room or she can't find her way home, let alone drive across town. The sadness that is being experienced is the loss of those dreams and expectations that will never take place.

Studies on Anticipatory Grief

Schulz et al (2003), in a study published in the *New England Journal of Medicine*, discussed the difficulties involved in the extended time spent caring for persons with dementia at the end-of-life. They determined that support was needed prior to the patient's death and that death itself often brought considerable relief. This was based on four (4) years of data provided by 217 family caregivers. The results showed that 90% of caregivers felt death was a relief to the patient and 72% felt the death was a relief to them. The researchers felt that grief support may have the largest benefit when provided in the period immediately preceding the patient's death. Caregivers also reported high levels of depression during the time of caregiving.

Marwitt, Mueser and Sanders (2004) developed a caregiver grief inventory (MM-CGI Short Form) that is helpful in working with family caregivers. It is based on a Likert scale with questions such as "*I've had to give up a great deal to be a caregiver*" and "*I feel*

very sad about what this disease has done” to “I will be tied up with this for who knows how long”. Asking the caregiver “In what ways has your life changed?” can be helpful and open the door to conversation. Unlike death-related grief, which begins at a single point in time, anticipatory grief for caregivers of person with memory loss begins with living circumstances and changes at multiple points in time.

What impacts anticipatory grief?

Psychological, social and physiological factors impact anticipatory grief.

Psychological factors include characteristics related to the nature and meaning of the relationship, the personality of the griever, and the characteristics of the illness itself.

Social factors include the dying individual’s knowledge and response to the illness and ultimate death, family dynamics and responses to the illness and impending death, and general socioeconomic and environmental factors.

Physiological factors include the physical health, the energy level and the amount of rest, sleep, and exercise available to and engaged in by the griever.

One major variable affecting anticipatory grief is *meaning and purpose*. What has given their life meaning? This is unique to each individual and could include skills, intellect, pleasure, work or volunteer experience, and faith. The list of what gives a person’s life meaning is limitless.

Understanding what is meaningful for those experiencing anticipatory grief may not be evident even with those who we have known for an extended period of time. Loss can manifest itself in many ways. It often appears as frustration, anger, anxiety or depression, just to name a few. Some experience the emotion, but cannot identify the loss.

Factors that influence the grief response

- Placement
- Pain Management
- Support Systems
- The role of caregiving

Different factors will affect the grief response. Here are some concepts to consider:

Is the patient in the home or a nursing home? How does the caregiver feel about that? If it was a difficult decision to place the person with memory loss, there may be unresolved feelings around that.

How much pain is the patient in? How well is it being managed? Frequently, pain is not adequately addressed in a person with memory loss. It is important for the caregiver to

advocate for their loved one. The family will remember the pain their loved one experienced long after the death.

What support systems are available? Which children are involved?

Sometimes one adult child or spouse takes on the caregiving responsibilities and then has resentment towards other family members. Also, long distance caregivers often feel helpless and may try to help by giving poorly received advice, albeit with good intention.

Often, the caregiver for a loved one with memory loss makes many life adjustments. Day after day, the caregiver may drive to the nursing home to visit or give their loved one a meal. If the person with memory loss is still living at home, the household routine may have been adjusted to accommodate those needs. Once the loved one dies, the caregiver will experience the loss of caregiving. For some it may be relief; for others, they will need to redefine their role in life.

Addressing Anticipatory Grief Issues

Four categories have been identified as helpful for families where a loved one has a chronic or terminal illness. By assisting families in these areas, they will be better equipped to manage the illness, problem solve, and address losses as they are experienced.

1. Adapting to the new and ever changing environment
2. Communication
3. Reflection
4. Legacy making

Adapting to the new and ever changing environment

When a family member has dementia, things are constantly changing. Often one feels they have just adapted to one situation and then a new crisis makes more change necessary. This can keep everyone in physical and emotional high gear. Losses are constantly happening. First, identify what loss is occurring. Initially, one may experience the feeling associated with the loss rather than the loss itself. Losses will become easier to identify as individuals become more aware of them. Normal responses to loss affect an individual in every arena of their life. These include physical, emotional, cognitive, and spiritual reactions.

It is important to discuss feelings once the losses have been identified. Sometimes individuals think they should not be experiencing certain emotions. When this happens, one often feels guilty or tries to suppress unwanted feelings. An important function of identifying and discussing feelings is to normalize them. Provide education and support to the griever about normal grief reactions that are consistent with loss. Let them know that there is nothing wrong with having these feelings. Then assist them in building and maintaining positive coping skills instead of developing bad habits or destructive behaviors in addressing grief reactions.

Another important aspect of adapting to the loss is to explore the meaning of the loss to the individual. Many losses may not have a major negative impact on an individual. For others, losses may be so devastating for the griever that they affect the way they respond to others. They can become angry or depressed and withdraw from life.

Adapting to change can be very difficult for many individuals depending on their expectations and cognitive abilities. Understanding the loss and finding ways to adapt can bring meaning and fulfillment back into the griever's life. For example, a person with memory loss may no longer be able to drive to the store, but he still can shop independently once at the store. It is important to focus on the remaining strengths or the capabilities.

Communication

- Importance of good communications
- Learn how to communicate feelings within the family
- Address unfinished business
- Relationship issues (I should have/wish....)

Communication between individuals can be difficult even when things are good. Many things impact effective communication such as individual characteristics, family systems, style and cultural norms. Learning how to communicate feelings is very important. It is through communications that we can learn what is meaningful for an individual and why they are responding in a certain way. It is important to communicate without hurting those you care about.

It is also through communication that we learn how losses are affecting a person. We can realize how unfinished business that is often displayed as frustration or anger. We can discover how the loss affects one's self esteem or self worth.

Communication is not easy when it comes to a chronic or terminal illness. So often you hear one of the caregivers say, "I wish he would just talk to me about what is happening." Remember that communication can be impacted by the disease process and one has to continuously learn how to interpret what is being said. The person with memory loss's ability to speak may deteriorate. The inability to use correct words can make communications more difficult; for example, an individual may be talking about his deceased wife but at times may refer to her as his "mother". Generally, the context within which the word is being used makes what the individual is trying to say more evident.

When there is little or no communication, relationships can become difficult to manage. An ability to communicate effectively may change quickly. Constant adjustment and creativity is required to keep the lines of communication open and to avoid frustration and anger which would shut them down.

Legacy and Reflection

- Create memory projects
- Encourage feelings regarding memories
- Ethical Wills

Other ways of managing anticipatory grief are through legacy and reflection techniques. Remembering and telling old stories, old pictures and music can often touch the person with memory loss. Long term memories, significant events and feelings of significance can be triggered. Good memories can be fuel for conversation and stories can be passed on from generation to generation, keeping the spirit of the person alive for future generations. In addition, reminiscences often provide the person with memory loss with feelings of meaning and purpose. These reflections and legacies are a gift to those left behind.

One legacy technique is the use of Ethical Wills. An ethical will is not a legal document that bequeaths valuables, but it is a way to pass on personal legacies and a way to bequeath personal values, beliefs, blessings, and advice. Ethical wills can be written, such as creating books, journals, poetry. They can be filmed or digitally recorded. Or, ethical wills can be expressed through art and music. They can be made with a person who may have significant memory loss. There is an ever expanding knowledge base on ways to create ethical wills, from college courses to the internet (see www.ethicalwill.com).

In Summary

The feelings of grief and loss experienced by those with dementia and their caregivers are not confined to the final stages of dementia. Caregivers nearly always experience anticipatory grief. Anticipatory grief occurs when there is an opportunity to anticipate death, as with a prolonged disease process. It includes past, present, and future losses. The caregiver experiences losses along a continuum and could possibly experience secondary losses after the patient dies. For example, a caregiver who goes to a nursing facility every day to feed a loved one may experience the loss of that activity and in addition to the loss of the patient after the death.

The last three months before the patient's death may be the hardest for caregivers due to unresolved issues. In fact, one of the greatest benefits provided by hospice for patients with dementia and their families is spiritual and grief counseling. Many caregivers have reported that hospice providers were especially well equipped to assist them with grief (Smith & Keene). While addressing the caregiver's anticipatory grief does not negate the deep sadness he or she will experience at the time of the patient's death, it may help the caregiver cope with the bereavement process.

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