



# Anticipatory Grief

## *An Evidence-Based Approach*

Julia Carl Shore, FNP-BC, ACHPN ○ Marianne Wientzen Gelber, GNP-BC, ACHPN ○  
Lauren M. Koch, ANP-BC, ACHPN ○ Emily Sower, ANP-C, ACHPN

Anticipatory grief is a symptom that can be experienced by caregivers and patients, especially those coping with advanced disease. Frequently, symptoms of anticipatory grief are disguised as depression, anxiety, or pain. This article reviews the concept of anticipatory grief, explores various assessment tools, and offers communication-based management strategies. Key nursing implications are also discussed.

### KEY WORDS

anticipatory grief, communication skills, death and dying, palliative care

Grief is a normal and expected reaction to loss. Anticipatory grief is an emotional response that is experienced before a true loss. Other terms for this prescient state include preparatory grief or premature grief. This specific subset of grief is an unconscious process that happens when stability is threatened, most often by a new and unwelcomed diagnosis.<sup>1</sup> Anticipatory grief encompasses the mourning, coping, and planning of one's life in response to an impending loss as well as future losses.<sup>2</sup> As losses of identity, function, and potentially loss of life accumulate along the illness trajectory, anticipatory grief processes continue to be triggered; the result is often an overwhelming cumulative loss effect.<sup>1</sup> Palliative care nurses are uniquely positioned to screen and treat anticipatory grief. This article aims to review tools and strategies to enhance the care of patients and caregivers suffering from anticipatory grief. As seen in the following case study,

**Julia Carl Shore, FNP-BC, ACHPN**, is senior nurse practitioner, Lillian and Benjamin Hertzberg Palliative Care Institute, Mount Sinai Hospital, New York.

**Marianne Wientzen Gelber, GNP-BC, ACHPN**, is senior nurse practitioner, Lillian and Benjamin Hertzberg Palliative Care Institute, Mount Sinai Hospital, New York.

**Lauren M. Koch, ANP-BC, ACHPN**, is nurse practitioner, Palliative Care Department, Overlook Medical Center, Summit, New Jersey.

**Emily Sower, ANP-C, ACHPN**, is nurse practitioner, Palliative Care Department, Sibley Memorial Hospital, Washington, DC.

Address correspondence to Lauren M. Koch, ANP-BC, ACHPN, Overlook Medical Center, 99 Beauvoir Ave, Summit, NJ 07901 (lauren.koch@atlanticehealth.org).

The authors have no conflicts of interest to disclose.

DOI: 10.1097/NJH.0000000000000208

interpreting a patient's emotional state is integral to providing the best care possible.

### CASE STUDY

Mrs Jones is a 42-year-old woman with metastatic breast cancer who has undergone a bilateral mastectomy, chemotherapy, and radiation. She is now hospitalized for new onset of severe headaches. She is well known to the palliative care team from her prior hospitalizations related to treatment complications and uncontrolled symptoms. She has a devoted husband and 2 children, aged 10 and 12 years. During past interactions, she has been vibrant, pleasant, and tolerant of the many burdens of her illness and treatment. Mrs Jones' oncologist discusses a new finding of brain metastasis and the lack of further chemotherapy options available and then leaves the room. Mary, the palliative care nurse, enters Mrs Jones' room to find her crying and slightly withdrawn, no longer at her measured baseline. What assessment tools and strategies do nurses have to address the potential range of emotions during this interaction?

### CONCEPTUAL FRAMEWORK

Nursing theories help to frame, explain, or define the provision of nursing. In the Roy Adaptation Model of Nursing, Dr Callista Roy<sup>3</sup> conceptualizes the person from a holistic perspective. Roy's model focuses on the interrelated biological, psychological, and social systems. Individuals strive to maintain a balance between these systems and the outside world with the goal of achieving an adequate level of coping. Persons with serious illness confront numerous stressors in their environment to which a coping response (either adaptive or maladaptive) is forced. This model consists of the following domain concepts: person, health, environment, and nursing. Nursing's goal is the promotion of adaptation in all 4 modes (physiological, self-concept, role function, and interdependence), thereby influencing the person's health, quality of life, and dying with dignity.<sup>3</sup>

Anticipatory grief for persons with serious illness and their family members could pose a threat to their integrity and demand adaptation if integrity is to be maintained. The goal of nursing is to help promote adaptation during health and illness. Utilizing Roy's Adaptation Model of Nursing aids nurses in facilitating positive adaptation of seriously ill patients



and their families as they cope with anticipatory grief, loss in multiple domains, and acceptance of limited prognosis, thus allowing for quality of life and a dignified death.<sup>3</sup>

## DEFINITION OF ANTICIPATORY GRIEF

Anticipatory grief is “described as a range of intensified emotional responses that may include separation anxiety, existential aloneness, denial, sadness, disappointment, anger, resentment, guilt, exhaustion, and desperation.”<sup>4</sup> Anticipatory grief can be a response to the loss of function, loss of identity, and changes in role, in addition to impending death.<sup>4</sup> Furthermore, anticipatory grief is experienced not only by the terminally ill person but also by family, friends, and caregivers.

A patient who has just received difficult news about her cancer may begin to show signs of anticipatory grief. Symptoms can span physical, emotional, cognitive, and spiritual domains. These symptoms can be experienced by both the patient and family. Examples of physical symptoms are similar to those experienced by loved ones after the anticipated death, that is, sleep and appetite disturbance, headache, nausea, and fatigue. Other individuals may feel anxious, sad, helpless, disorganized, forgetful, or angry. Doubting one’s faith or questioning the existence of God is not unusual. Overall, people may also notice difficulty in connecting emotionally with others.<sup>4</sup>

Unfortunately, anticipatory grief rarely eliminates or ameliorates the grief one experiences after the actual death. However, the experience of anticipatory grief can be beneficial in that one has time to prepare and develop coping skills for the inevitable changes to come.<sup>5</sup> As palliative care and hospice providers, it is essential that we identify patients and families experiencing anticipatory grief in order to assess for complications, provide support, and nurture effective interventions to aid in coping.

## ASSESSMENT OF ANTICIPATORY GRIEF

Evaluating for anticipatory grief involves an initial assessment of depression and anxiety in patients and family members.<sup>6</sup> Symptoms of depression and anxiety may increase in patients with terminal illnesses and their families and can contribute to the suffering experienced.<sup>6</sup> Identifying clinical levels of depression and anxiety beyond generalized sorrow can be challenging for clinicians. Useful tools for performing this important evaluation include the Hospital Anxiety and Depression Scale, the Geriatric Depression Scale, or the Beck Depression Inventory.<sup>7</sup> These tools have been validated to be effective in the screening for psychiatric conditions in patients with advanced illness. These tools involve self-screening questionnaires, ranging from 14 to 21 questions that can be used to quickly identify depression and anxiety in these seriously ill patients.

A complete symptom assessment follows the mental health evaluation. Symptom management is paramount as uncontrolled symptoms such as pain and dyspnea can exacerbate existential sources of suffering. In addition, uncontrolled symptoms can increase the suffering of the family members who are witness to the patient’s distress.<sup>7</sup> Once a general evaluation is complete and symptom control is optimized, the nurse can continue the assessment for anticipatory grief.

The anticipatory grief tools that can be utilized with patients and family members are the Preparatory Grief in Advanced Cancer Patients Scale (PGAC), Anticipatory Grief Scale (AGS), and the Marwit-Meuser Caregiver Grief Inventory (Table 1). The PGAC is a 31-item self-assessment scale developed to measure anticipatory grief responses within a singular population. The reliability and validity of the PGAC tool have been established, and it was also deemed acceptable by the population studied, which included Greek patients with advanced cancer.<sup>8</sup> Likert scales ranging

**TABLE 1** Assessment Tools for Anticipatory Grief<sup>a</sup>

Tool	No. of Items in Tool	Number on Likert Scale	Cronbach’s Alpha
The Preparatory Grief in Advanced Cancer Patients Scale <sup>8</sup>	31-Item self-assessment scale that measures anticipatory grief in Greek patients with advanced cancer	4-Point Likert scale ranging from 0 (disagree) to 3 (agree)	Overall Cronbach’s $\alpha$ of .838 and ranged between .823 and .864
Anticipatory Grief Scale <sup>9</sup>	27-Item self-administered scale that measures the bereavement experience of female spouses of dementia patients	5-Point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree)	Cronbach’s $\alpha$ of .84
Marwit-Meuser Caregiver Grief Inventory <sup>10</sup>	50-Item self-report scale that measures grief response of family caregivers of people with Alzheimer disease	5-Point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree)	Overall Cronbach’s $\alpha$ of .833 and ranged between .80 and .90

<sup>a</sup>Helps to differentiate between normal and pathological anticipatory grief processes and in identifying those experiencing anticipatory grief.



from 0 (disagree) to 3 (agree) are utilized for the analysis. Assessment items were determined by literature reviews and clinical familiarity with the patient population. Domains included in the scale include self-consciousness, adjustment, sadness, anger, spirituality, and social support.<sup>8</sup> Clinicians are encouraged to utilize this tool to identify patients in need of more formalized clinical support.

The second tool, aptly named the “Anticipatory Grief Scale” (AGS), was developed to measure the bereavement experience in female spouses of persons who received a diagnosis of dementia. The 27-item self-administered questionnaire assesses coping mechanisms and self-perceived reactions to impending loss.<sup>9</sup> Like the PGAC, Likert scales are used to analyze responses. Although originally developed for relatives of patients with dementia, other studies have modified the wording for use with other diseases; these modified scales have not been validated.<sup>11</sup> The advantage of using AGS is that clinicians, social workers, and counselors can identify the problems patients and family members are experiencing prior to death so that proper interventions can take place to hopefully avoid long-term negative outcomes.<sup>11</sup>

The third tool, Marwit-Meuser Caregiver Grief Inventory, is a 50-item self-report scale used to measure grief response of family caregivers of people with Alzheimer disease.<sup>10</sup> This scale examines the personal sacrifices being made by the caregivers, sadness and longing, and worry and isolation.<sup>10</sup> This self-report produces a total grief scale, with higher levels of grief indicating anticipatory grief. This tool has been determined to be valid and reliable in this population. A disadvantage of this tool is that it is specifically designed for caregivers and not patients (Table 1).

While there is no criterion-standard assessment tool to aid clinicians in differentiating between normal and pathological anticipatory grief processes,<sup>12</sup> these tools are helpful in identifying patients and family members experiencing anticipatory grief. Additional research is needed to establish a well-validated measurement tool that is applicable to a wide variety of populations and easy to administer.

## MANAGEMENT OF ANTICIPATORY GRIEF

As previously mentioned, anticipatory grief can manifest as a wide spectrum of physical, emotional, cognitive, and spiritual signs and symptoms.<sup>5</sup> It is important for providers to recognize the symptoms associated with anticipatory grief in order to manage the experience and respond in an appropriate and meaningful way. Ideally, this would be done in close collaboration with an interdisciplinary team including social workers and chaplaincy.

In a study published in 2011, Johansson and Grimby<sup>11</sup> found that almost half the relatives of patients receiving palliative care sought the support of nurses. This finding reflects the importance of clinical staff readiness to respond

to anticipatory grief. Nurses can expect the intensity of anticipatory grief to grow as the time of death nears, often requiring additional support. The most helpful support is often delivered in the form of providing information regarding anticipatory grief, identifying and normalizing the experience, and addressing somatic concerns.<sup>6</sup> Education regarding somatic complaints may come in the form of sleep hygiene, nutritional guidance, or referrals to spiritual care. Nurses are essential in providing end-of-life care because of their dual roles as patient advocates and clinicians.<sup>6</sup> Providing daily information and regular updates on the patient's condition reduces the anxiety of both patients and families. In addition to facilitating open communication, frequent and thorough updates can ease fears around patient suffering and offer families and caregivers peace of mind.<sup>6</sup>

In addition, exploring past coping mechanisms with the individual and family will provide information regarding previously effective supportive measures and help to establish new coping abilities. It is important to evaluate for potentially harmful coping strategies, such as the reliance on alcohol, illicit substances, and other unhealthy behaviors.<sup>11</sup>

Attention to symptom control with a particular emphasis on pain management has been found to be especially important. Nurses directly provide comfort-focused care and symptom management for this patient population, and they are aware of the importance of close monitoring for modifiable symptoms. In actively alleviating both patient and family suffering, the nurse offers a healthy environment for the expression of anticipatory grief.

Utilization of specific communication strategies can be an additional tool to manage patients', families', and caregivers' anticipatory grief. Four effective communication strategies that hospice and palliative care providers can use are (1) ask-tell-ask, (2) NURSE statements, (3) “I wish” statements, and (4) silent presence. The ask-tell-ask strategy is an invitation to the group or individual to talk about current feelings and medical situations.<sup>13</sup> The NURSE framework focuses on recognizing, responding, and validating emotional responses of patients, families, and caregivers.<sup>13</sup> The NURSE acronym stands for (N) name the emotion, (U) understand the emotion, (R) respect what the patient tells you, (S) support the patient, and (E) explore the patient's concerns (Table 2). “I wish” statements help to acknowledge the difficult realities of the patient's prognosis as they grieve many losses—of health, changes in role identity, family structure, and independence.<sup>14</sup> When using such statements, “clinicians temporarily suspend their role as scientists and medical experts and respond as human beings faced with overwhelming circumstances that are not of their own choosing.”<sup>15</sup> A final communication strategy is silent presence, which provides support and establishes space for decision making.<sup>16</sup> Using these 4 communication techniques not only supports patients, families, and caregivers,



**TABLE 2** Toolbox of Communication Skills Nurse Statements<sup>a</sup>

N: name the emotion	"I see you are very frustrated."
U: understand the emotion	"It sounds like this has been a long, hard journey for you and your family."
R: respect what the patient, family, or caregiver tells you	"Your love and devotion to your children and family have been so evident to the staff."
S: support the patient, family, and caregiver	"You don't need to do this alone. Our team will be here to help you along the way."
E: explore the patient, family, or caregiver concerns	"Can you tell me more about what worries you?"
<sup>a</sup> A framework of communication which focuses on recognizing, responding and validating emotional responses. <sup>15</sup>	

but also ensures them that their health care team will not abandon them (Table 2).

## CLINICAL SCENARIO

To illustrate how these techniques can be used, let us revisit Mrs Jones, the 42-year-old woman who received a diagnosis of metastatic breast cancer 4 years ago. Her oncologist has just left the room after speaking with her about the results of the computed tomography scan of her brain. Mary, her palliative care nurse, has known the patient from prior visits.

Nurse Mary enters Mrs Jones' room to find her crying and holding her head in her hands. Mary sits quietly at the patient's bedside and reassuringly places a hand on the patient's shoulder (silence). After a few minutes, Mrs Jones begins to speak:

Mrs Jones: "Dr Smith just gave me bad news about my head CT (computed tomography) scan."

Mary: "Would it be helpful for us to talk about what Dr Smith told you?" (Ask-tell-ask)

Mrs Jones: "He told me the cancer has spread to my brain."

Mary: "Can you tell me more about what else he said?" (Explore statement)

Mrs Jones: "He said the cancer in my brain is what has been causing my headaches. My cancer is everywhere. There is no more treatment for me. I am going to die."

Mary: "I can only imagine how devastated you must feel." (Name statement)

Mary: "I wish the news was better for you and that we had better and stronger medicines for your cancer." ("I wish" statement)

Mrs Jones: "I thought I did everything I was supposed to do so that the cancer wouldn't spread. I am so upset and shaken by this news."

Mary: "It sounds like this has been a long, hard journey for you." (Understand statement)

Mrs Jones: "I wanted to beat this disease. I need more time with my children and husband. My children are just babies. They are only 10 and 12."

Mary: "Your love and devotion to your children and family have been evident since you began treatment. You did everything you were supposed to do." (Respect statement)

Mrs Jones: "I really wanted as much time as possible with my kids. Now I don't know what I should tell them—or even how and when to say it."

Mary: "I hear your concerns about your children and your husband. You don't need to do this alone. Our team can help you." (Support statement)

Mrs Jones: "Thank you."

Mary: "Can you tell me more about your concerns about the children?" (Explore statement)

Mrs Jones: "I am really worried about how to break this to the kids. I have only told them a little bit about my cancer since they are so young. I didn't want to frighten them. Maybe that was wrong of me? Now I have to tell them I am going to die."

Mary: "You know your children the best, and your approach was right for them at that time. There are many ways our team can help you and your family now that you have to explain this difficult news. Would you like to hear more about how we may be able to help?" (Ask-tell-ask)

Mrs Jones: "Yes, okay."

Mary: "Our team consists of your oncologist and oncology nurses, but also a specially trained social worker, massage therapist, art therapist, and chaplain. We will do everything we can to support you and your family (support statement). For example, our staff can help you share news with your husband if you would like. We can also plan with you



and your husband about how to explain the situation to the children and make sure they get the support they need. Would these things be helpful?" (Ask-tell-ask)

Mrs Jones: "Yeah, I just felt so alone and overwhelmed this morning. I think I feel a little bit better knowing that you can help me figure out how to break this to my family. But I still just can't believe the cancer has spread so much, and there is no more therapy for me."

(Silence)

Mrs Jones: "I feel better knowing that you can help me speak with my family."

Utilizing these communication skills will allow palliative care and hospice providers to optimize care and support for patients, families, and caregivers experiencing anticipatory grief.

## KEY IMPLICATIONS FOR PALLIATIVE NURSING

Palliative care and hospice providers encounter patients, families, and caregivers experiencing anticipatory grief on a daily basis. Given this overwhelming exposure, it is essential for providers to have a clear understanding of anticipatory grief and the skills necessary to best support patients, families, and caregivers.<sup>17</sup> Providers need to be able to identify those experiencing anticipatory grief by utilizing the various assessment tools available. Once those experiencing anticipatory grief are identified, providers can find it useful to use various interventions and strategies. These interventions include identifying physical and psychological symptoms and treating them with pharmacologic and nonpharmacologic therapies, providing support and education to patients, families, and caregivers, and utilizing empathetic communication strategies.

## CONCLUSIONS

Further research and education highlighting nursing communication in a palliative care population would be bene-

ficial. Nursing is the sole profession represented by the authors, posing a potential limitation of the article; a more comprehensive approach would be to elicit social work, chaplaincy, and physician perspectives as well.

## References

1. Rando TA. *Loss and Anticipatory Grief*. Lexington, MA: Lexington Books; 1986.
2. Ferrel B, Coyle N. *Oxford Textbook of Palliative Nursing*. New York: Oxford University Press; 2010.
3. Roy C. Research based on the Roy Adaptation Model: last 25 years. *Nurs Sci Q*. 2011;24(4):312-320.
4. Garand L, Lingler JH, Deardorf KE, DeKosky ST, Schulz R, Reynolds CF 3rd, Dew MA. Anticipatory grief in new family caregivers of persons with mild cognitive impairment and dementia. *Alzheimer Dis Assoc Disord*. 2012;26(2):159-165.
5. Hottensen D. Anticipatory grief in patients with cancer. *Clin J Oncol Nurs*. 2010;14(1):106-107.
6. D'Antonio J. Caregiver grief and anticipatory mourning. *J Hosp Palliat Nurs*. 2014;16(2):99-104.
7. Hultman T, Reeder EA, Dahlin CM. Improving psychological and psychiatric aspects of palliative care: the National Consensus Project and the National Quality Forum preferred practices for palliative and hospice care. *Omega (Westport)*. 2008;57(4):323-339.
8. Mystakidou K, Tsilika E, Parpa E, Katsouda E, Sakkas P, Soldatos C. Life before death: identifying preparatory grief through the development of a new measurement in advanced cancer patients (PGAC). *Support Care Cancer*. 2005;13(10):834-841.
9. Johansson AK, Sundh V, Wijk H, Grimby A. Anticipatory grief among close relatives of persons with dementia in comparison with close relatives of patients with cancer. *Am J Hosp Palliat Care*. 2013;30(1):29-34.
10. Holley CK, Mast BT. Predictors of anticipatory in dementia caregivers. *Gerontologist*. 2009;49(3):388-396.
11. Johansson AK, Grimby A. Anticipatory grief among close relatives of patients in hospice and palliative wards. *Am J Hosp Palliat Care*. 2012;29(2):134-138.
12. Mystakidou K, Tsilika E, Parpa E, Galanos A, Vlahos L. Caregivers of advanced cancer patients: feelings of hopelessness and depression. *Cancer Nurs*. 2007;30(5):412-418.
13. Brobäck G, Berterö C. How next of kin experience palliative care of relatives at home. *Eur J Cancer Care*. 2003;12(4):339-346.
14. Harrington V, Lackey NR, Gates MF. Needs of caregivers of clinic and hospice cancer patients. *Cancer Nurs*. 1996;19(2):118-125.
15. Quill TE, Arnold RM, Platt F. "I wish things were different": expressing wishes in response to loss, futility, and unrealistic hopes. *Ann Intern Med*. 2001;135(7):551-555.
16. Wong MS, Chan SW. The experiences of Chinese family members of terminally ill patients—a qualitative study. *J Clin Nurs*. 2007;16(12):2357-2364.
17. Back A, Arnold R, Tulsy J. *Mastering Communication With Seriously Ill Patients: Balancing Honesty With Empathy and Hope*. New York: Cambridge University Press; 2010.

For more than 55 additional continuing education articles related to hospice and palliative care, go to [NursingCenter.com/CE](http://NursingCenter.com/CE).