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Post-Traumatic Stress Disorder Related to Cancer: Hope, Healing, and Recovery

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Post-traumatic stress disorder (PTSD) is defined as a psychiatric diagnosis “indicative of a disturbance of the normal capacity to resolve cognitive and emotional responses to a traumatic event” (Johnson, 2009, p. 3). PTSD is a complex, chronic disorder of overlapping comorbid symptoms, including anxiety and depression. Traumatic events such as the cancer experience are insufficiently processed by the individual, and symptoms can be reactivated by environmental or social triggers (Johnson, 2009). Childhood trauma is an identified risk factor for PTSD later in life (Fairbank, Putnam, & Harris, 2007); therefore, I must acknowledge my childhood, my young adulthood, and, foremost, my siblings. They are role models of perseverance in their own professional accomplishments and their unselfish dedication to society. I love them dearly.

My brother, Bill Gibson, a retired Army lieutenant colonel, works at the Pentagon and suffered the loss of friends and colleagues in the 9/11 attack. He volunteers every other weekend as a police officer in Washington, DC. My sister Carole Browne, PhD, is a researcher and professor of cellular biology at Wake Forest University in Winston-Salem, NC. Her microscopy research has contributed to the understanding of oncogenesis, and, throughout her accomplishments, she has survived bipolar depression. My younger sister Cindy Lodwig, BA, MA, is an elementary science teacher and also an eight-year survivor of breast cancer. Last, my youngest sister, Beth Morris, BA, has been a single mother and is now a director of human resources at the University of Pittsburgh in Pennsylvania.

My siblings were an anchor amidst a chaotic and often emotionally and physically abusive childhood. My father had narcissistic personality disorder and my dear mother has borderline personality disorder. Her love

ranges from unconditional to raging outbursts of hate. My father, born and raised in the Midwest, bought a 46-foot cabin cruiser although he had never experienced boating, let alone been at the helm. My mother did not know how to swim and was deathly afraid of water. She never set foot on the moving boat without a life jacket. This is a metaphor for their relationship, and as a family we faced many rough seas.

Behind every psychiatric diagnosis—whether anxiety, depression, or PTSD—there is a human being whose life has been forever changed physically, emotionally, mentally, and spiritually. Reflecting back to childhood, we all can probably recall from personal memory or family stories our personalities, nicknames, individuality, and character. As the middle child of five, I was known to my family as the “happy child with the smiling face.” My mother tells the story that, by kindergarten, I would be devastated when I felt someone did not respond to me with equal love and attention, always chanting, “Doesn’t everybody love me?”

My parents bitterly divorced at the time of my adolescence and my father abandoned our family, physically and financially. During my high school years, I became a mother figure to my younger two sisters, ages eight and six, as my older siblings went off to college. Life as I had known it became no less traumatic as my mother sunk into a deep depression and became emotionally unavailable. It was not unpredictable that I would choose nursing as my career. My natural caretaking tendencies were solidified in the tender years of adolescence and feelings of safety and trust were rocked to the core. I was codependent before it became fashionable.

My enthusiasm to begin my professional nursing career can be summed up by artist Leigh Standley (2007a), “I am fairly certain that given a cape and a nice tiara, I could save the world.” I am sure that most nurses can

share these sentiments. It is the dedication and empathic engagement that nurses, especially oncology nurses, share with their patients and families that make them vulnerable to degrees of PTSD, termed vicarious traumatization, secondary traumatic stress, and compassion fatigue (Bush, 2009a). Nurses who have experienced significant trauma or grief and loss in their personal lives are at a greater risk for developing secondary traumatic stress. It is the highly motivated, idealistic, and highly empathic caregivers who are most vulnerable to burn out, “. . . as does a bright flame by virtue of its intensity” (Larson & Bush, 2006, p. 588).

I won the tiara at age 17 when I was named “Junior Miss” of my small town of Wareham, MA. I earned the cape when I graduated with my master’s degree in oncology nursing in 1982. But I assure you, I have the wisdom now to know that I cannot save the world but that I can certainly make a significant difference with my presence.

At age 28, two months prior to graduating as a clinical nurse specialist in oncology, I encountered my first diagnosis with cancer—malignant melanoma. Another trauma met with emotional pain and disappointment but balanced with hope and resolve. Not until further along in my life journey did I fully understand that the impact of a cancer diagnosis is influenced greatly by the developmental stage of the person’s life. My initial insecurity at that time was fear about my ability to establish appropriate professional boundaries as a clinical nurse specialist at the same time that I had become a patient with cancer. I also wanted to start a family, but for three consecutive years was advised against the risk of pregnancy and recurrence.

Four years prior to my diagnosis, I had married my college sweetheart, a curly-headed shortstop on his way to play professional baseball until he was diagnosed with a chronic muscular disease, polymyositis. He was placed on a clinical trial of azathioprine and high-dose prednisone through the National Institutes of Health and, after the initial five years of treatment, he regained strength and a sense of normalcy. Forging ahead with a positive and hopeful attitude, my husband and I began to build our lives around integrating our illnesses but simultaneously holding tight to our dreams.

Historical Framework of Post-Traumatic Stress Disorder

Symptoms of PTSD have been illustrated in the psychiatric literature since at least the 1800s, describing symptoms following war or catastrophic events in history. The phrase “fright neurosis” was used to capture anxiety symptoms after accidents and injuries (Friedman, Keane, & Resick, 2007; van der Kolk, 2007) (see Figure 1). Following World War II, the American Psychiatric Association ([APA], 1952) produced the

first *Diagnostic and Statistical Manual of Mental Disorders*, known as the *DSM-I*. At that time, the diagnosis of residual anxiety related to any trauma was known as “gross stress reaction” (Friedman et al., 2007, p. 3). Interpreted by some as a political statement, the *DSM-II* (APA, 1968) was published at the height of the Vietnam War and the category was eliminated. The history of trauma studies in psychiatry illuminates the intimate connection among cultural, social, historical, and political conditions that have influenced the study of PTSD. Cultural forces included the status of women and children in society, funding for specific research endeavors, and other economic and political influences (Friedman et al., 2007; van der Kolk, 2007).

The 1970s brought social movements to the United States that drew attention to anxiety-related combat stress, interpersonal violence, and assault, including rape and physical assault on both men and women. These traumatic incidents were termed rape trauma syndrome, child abuse syndrome, and battered woman syndrome (van der Kolk, 2007). Symptoms following these traumas were similar to the symptoms described by Vietnam War veterans. In 1980, the APA expanded criteria for PTSD to be classified as an anxiety disorder in the *DSM-III* (APA, 1980). Reactions to all traumatic experiences were pooled into one defining category: PTSD. Research was spawned and treatment outcome studies were published by the mid to late 1980s.

Diagnostic and Statistical Manual of Mental Disorders-IV Criteria for Post-Traumatic Stress Disorder

The *DSM-IV-Text Revision* was published in 2000 and expanded criteria for PTSD outlined in the *DSM-III* (see Figure 2). *The DSM-IV* established new diagnostic criteria for acute stress disorder. Acute stress disorder is differentiated from PTSD in the *DSM-IV* and is identified as a psychiatric disorder if the stress occurs for one month following a traumatic incident. Distinct criteria for a

DSM-I	<ul style="list-style-type: none"> • Fright neurosis • Gross stress reaction
DSM-II	<ul style="list-style-type: none"> • Height of Vietnam War • Diagnostic criteria eliminated
DSM-III	<ul style="list-style-type: none"> • PTSD defined as anxiety disorder • Research and outcome studies

Figure 1. Historical Framework of Post-Traumatic Stress Disorder (PTSD) in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*

Note. Based on information from Friedman et al., 2007.

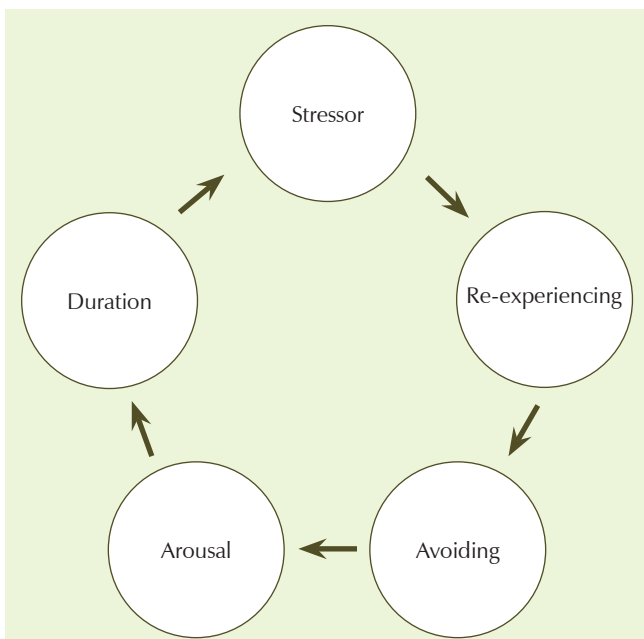


Figure 2. Diagnostic and Statistical Manual of Mental Disorders-IV Criteria for Post-Traumatic Stress Disorder

Note. Based on information from American Psychiatric Association, 2000; Friedman et al., 2007.

diagnosis of PTSD include the occurrence of a stressor that can be differentiated from ordinary stress, re-experiencing symptoms related to the traumatic event, feelings of numbing or withdrawal, symptoms of hyperarousal, and the duration of symptoms. PTSD is diagnosed as acute if the duration of symptoms lasts less than three months after exposure to the trauma and as chronic if symptoms last more than three months. Delayed onset also is specified with the diagnosis and is supported if the onset of symptoms is at least six months after traumatic exposure (Friedman et al., 2007; Johnson, 2009).

Diagnostic and Statistical Manual of Mental Disorders-IV Symptom Cluster

The *DSM-IV* includes 17 symptoms that define the syndrome of PTSD within three symptom clusters: re-experiencing the trauma, avoidance and numbing, and the state of hyperarousal (Johnson, 2009) (see Figure 3). The initial step in diagnosing PTSD is establishing and identifying exposure to an extreme stressor. The *DSM-IV* defines extreme stressor as having three elements: the type of traumatic exposure; distinguishing the traumatic stress from ordinary, normal stress; and identifying an event that triggers an intense emotional response (Johnson, 2009). An assessment guide includes evaluation such as, “Are the presented symptoms within the normative range of reaction to such an experience or is the symptom representative of a pathologic or clinically significant problem?” (Johnson, 2009, p. 5). If an indi-

vidual presents for assessment or treatment following a prior or current traumatic exposure, the patient with PTSD will present with a distinct change from his or her previous behavior and level of functioning.

The individual’s symptoms may include flashbacks, traumatic daydreams, or nightmares that bring the past trauma into the present psyche (Johnson, 2009). Traumatic memories can be triggered by stimuli that remind the individual of the traumatic event or the memories can have a “frozen-like” quality that consists of images and sensations—taste, smell, touch, and sound—that remind the individual of the experienced trauma. Re-experiencing the event in the present may contribute to the individual avoiding stimuli associated with the event or the individual becoming overall numb, possibly presenting with a flat affect, feelings of detachment or estrangement from others, or even an inability to recall the most troubling aspects of the trauma (Johnson, 2009).

Hyperarousal causes the individual’s nervous system to always be on the alert for danger. Sleep patterns become disrupted and the person becomes vigilant, presenting an exaggerated startle response. Expressions of feeling jumpy, on edge, or irritable are common. Anger can be easily evoked with a minimum of frustration. The person also may complain of difficulty concentrating, staying on task, or completing daily activities (Johnson, 2009).

Defining Characteristics of Post-Traumatic Stress Disorder

Defining characteristics of PTSD can be the result of directly experiencing, witnessing, or knowing about the traumatic event. The event involves actual or perceived threat to life or the physical integrity of oneself or others. The response is the same—intense fear, feelings of helplessness, or extreme horror (Friedman et al., 2007; Johnson, 2009). The symptoms must be present for at least one month and interfere with physical, emotional, social, and occupational functioning.

Ability to Cope With Trauma

Many variables will influence the individual’s response and ability to cope during and after a traumatic experience (see Figure 4). Two important factors include the individual’s innate ability and learned ability to cope. Other factors that influence coping include prior experiences of trauma, chronic stressful life experiences, stressors occurring at the time of the event, genetic predisposition to psychological trauma, perceived ability to cope, internal resources such as resiliency and optimism, and perceived level of family and social support (Johnson, 2009).

Since the 1970s, the impetus for understanding the effects of trauma on social, psychological, and biologic functioning has continued to come from participation

Re-experiencing the trauma

Recurrent dreams, recollections, and intrusive thoughts

Avoidance and numbing

Feelings of detachment and diminished interest

State of hyperarousal

Startle reflex, insomnia, and memory impairment

Figure 3. Diagnostic and Statistical Manual of Mental Disorders-IV Symptom Cluster

Note. Based on information from American Psychiatric Association, 2000; Friedman et al., 2007; Johnson, 2009.

of individuals who themselves were exposed to trauma, such as Vietnam War veterans. PTSD began to be recognized and differentiated from acute anxiety disorder after the return of soldiers from the Vietnam War (Friedman et al., 2007; van der Kolk, 2007). In addition to U.S. involvement in foreign wars, Americans have suffered extreme trauma within our own boundaries. The first responders (i.e., fire, police, and medical personnel) to these traumatic events inevitably are also at a high risk for PTSD. And, in today's society, technology and the media have brought these traumas into our homes. Many of us will always remember our exact place in time when our own lives abruptly stopped via televised visions of the Oklahoma City bombing or the twin towers collapsing on 9/11.

My husband hollered for me in time to view the second airplane hit. Across the country, my family, immobilized with fear, sat by our televisions and phones to hear of any developments during the terrorist attacks. My brother was a civilian contractor at the Pentagon, and we did not hear of his safety until late that evening. My youngest sister, Beth, lived in Pennsylvania, close enough to the crash of Flight 93 to be called at work because the school that her two young boys attended had to be evacuated. Even the youngest children in the country could sense the fear of their caretakers and the sudden invasion on their safety that customarily embraced their daily lives.

The United States is involved in foreign wars in Iraq and Afghanistan, and the world has suffered from many natural disasters. Most recently, the Haiti earthquake demonstrated that the United States continues to aid those in need all over the world. Fairbank et al. (2007) asserted that the exposure to traumatic events for individuals in our society has "risen to the level of a public health problem" (p. 234). The introduction of PTSD into the *DSM*, as with many diagnoses that have been added, then deleted, then reconsidered, has not been without controversy that continues today (Friedman et

al., 2007). If you look into the eyes of a person suffering from PTSD, you may see the soul of anguish and suffering. Yet, in the fable *The Little Prince* by Antoine de Saint-Exupéry (1943), the fox says to the little prince, "It is only with the heart that one can see rightly. What is essential is invisible to the eye" (p. 63).

Post-Traumatic Stress Disorder Related to the Cancer Experience

It has been well understood that, for the majority of people, the fight against cancer is unknown, frightening, and a threat to self-integrity. Until the last decade, what has not been known is that some patients do not psychologically recover from the diagnosis, treatments, and unpredictable future as readily as others. The cancer experience may very well contribute to long-term stress and psychosocial morbidity.

I was on a family reunion on the Central Coast of California for the July 4th holiday in the summer of 2007. I woke up with general malaise and a lack of appetite but without any discernable symptoms. The family packed up and walked to the beach to enjoy the annual fireworks. Halfway through the wonder of beautiful colors shooting across the ocean waves, I had to leave because of overwhelming fatigue. I woke during the night, swung my legs to the floor, and the sharp pain that shot from my lower right abdomen buckled me to my knees. My husband and I jaunted off to a small 90-bed hospital. Using my nurse practitioner skills, I began to inform the nurses and doctors that I must have appendicitis even though the classic symptoms were absent. Politely, each healthcare provider told me that I was the patient now and that they would be doing the diagnosing, not me.

Upon waking in the recovery room, I smiled like the Cheshire cat and immediately pronounced that, indeed, I must have had appendicitis. When blank faces glanced back at me, I felt a pit in my stomach. The nurse went to the waiting room to have my husband come in before informing me that a 5 cm tumor was found on my appendix. The information given was information I understood. The cells were dysplastic and dedifferentiated of unknown origin (Bush, 2008).

Actual or threatened death or injury

Fear, terror, and helplessness

Figure 4. Defining Characteristics of Post-Traumatic Stress Disorder

Note. Based on information from American Psychiatric Association, 2000; Friedman et al., 2007.

To repeat the stages of shock and disbelief to oncology nurses is a moot point. I did not cry until later that evening after my husband had left my bedside and the surgeon made very late evening rounds. He informed me gently that most likely advanced appendiceal cancer was the diagnosis and, after staging, a right hemicolectomy would be necessary. After bursting into uncontrollable sobs that night, I can only remember two other times during my cancer journey when I was that stunned in disbelief. The next bout of flooding tears came when a right breast tumor was found during my workup for the appendiceal tumor. A mammogram nine months earlier had been negative. A physician I had known for 25 years could not look me in the eyes when he came into the treatment room with my biopsy report. As soon as he exited, I crumbled into a childlike, helpless mound and sobbed loudly with a special oncology nurse-angel holding me tightly with my husband by my side.

In less than six weeks, I had an appendectomy, right hemicolectomy, a total abdominal hysterectomy, two lumpectomies, and sentinel node biopsy. The total hysterectomy demonstrated primary ovarian cancer metastatic to the appendix (Bush, 2008). Numbness and disbelief followed. How could this be? An abdominal ultrasound and gynecologic examination a year before had been uneventful. The world seemed to come crashing down around me when I was informed that six cycles of paclitaxel/carboplatin were to be carried out, followed by seven weeks of radiation for the breast. Once again I found myself in a puddle of tears with another oncology nurse-angel holding my hand. What did I think of first? Alopecia and fatigue. What did I think of second? The courage of the patients I cared for daily and the optimistic messages I gave them of hope and endurance. I felt fortunate that my breast cancer was stage I, and because of the contiguous nature of the ovarian tumor, it was diagnosed at stage IIb.

I took a leave of absence from my nurse practitioner job in the breast clinic where I was employed, positively certain I would return to the position that I loved dearly. I expected to lose my hair between 14 and 17 days after the first cycle of chemotherapy, just as I always informed my patients. My son was ready, and so was I, when the first clump of hair could be pulled out on the 14th day. He shaved my head first, and, after watching my soft blonde locks fall to the floor, I watched his curly brown locks fall. He shaved his head in support. I felt prepared. I thought I knew exactly what to expect each step of the way across the journey. I believed that being an oncology nurse brought me the gift of knowledge and support—I could be as brave as the patients I so dearly cared for. I faced a few complications from treatment, including an abdominal wound infection and a pulmonary embolism, but I felt emotionally and physically up to the challenges. So I thought.

Upon finishing radiation therapy, I was exhausted. The fatigue was overwhelming, but still I was determined to return to my beloved work as soon as my group of four oncologists gave me the go ahead. However, weeks passed and I never felt the get-go. I woke up eight weeks later still bald, overweight and bloated, fatigued, clumsy with neuropathies in my hands and feet, and unable to think straight. It didn't take long to hit the wall (Bush, 2009b). I realized that, physically and emotionally, I could not return to my previous nurse practitioner position with its 10-hour days and an hour or more commute each way. And how could I work with breast and ovarian patients when I was still in recovery myself? Over time, I was experiencing all the same emotions that my patients always shared with me (Bush, 2009b).

Was I still myself or was there a new me and a new normal I had to integrate? Why was I crying now? The worst was behind me. I used fun, humor, preparedness, and determination to get through the first part of my journey. Why was I depressed now? Why was I not happy and proud to be a survivor with positive statistics on my side? Where had all my friends and colleagues disappeared to? They transitioned back into their lives without me. I felt left behind. I was lonely. My husband and son were attentive, but I felt that I suddenly had an empty heart and empty hands to offer.

The diagnostic criteria in the *DSM-IV* (APA, 2000) specifically added that being diagnosed with a life-threatening illness is an example of a traumatic event. Therefore, individuals with a history of cancer should be evaluated and considered to be at risk for developing PTSD. The National Cancer Institute (NCI, 2010) estimated that approximately 3%–4% of early-stage patients meet the diagnostic criteria for PTSD, with the rate increasing to 35% for those patients evaluated after treatment ends. It is estimated that, when the incidence of PTSD symptoms are present but do not meet the full syndrome of *DSM* criteria, the rates are higher, ranging from 20% in patients with early-stage cancer to 80% in those with recurrent cancer.

Realistically, active treatment for cancer never entirely ends. Once diagnosed, there continues to be consistent follow-up examinations, blood tests, and scans. If for any reason a questionable symptom arises, the investigation for recurrence intensifies along with the patient's anxiety and fear. On the continuum of cancer, the stage of recurrence has been found to be more stressful than the stage of diagnosis; when disease recurs, the hope for cure is gone (Bush, 2006). Individuals with a history of prior PTSD also are considered at a higher risk for continued emotional distress.

The experience of cancer differs from other PTSD-related trauma because of the difficulty in identifying one discrete stressor within the multiple crises that occur along the cancer trajectory. Smith, Redd, Peyser, and Vogl (1999) asserted that the cancer continuum is comparable

to another well-documented trauma—active military combat. A police officer who served in the Vietnam War explained the essence of time freezing: “Sometimes, in the thick of things, you may not even know you were hit until afterward, and sometimes it can take months, even years, before we find out how deep that wound might be” (Levine, 2005, p. 67). Having cancer, like being in combat, consists of periods of passive vigilance during remission interspersed with episodes of high arousal at follow-up examinations or if recurrent disease—the enemy—is suspected. The body fights cancer with its own immune resources and depends on the medical weapons of surgery, chemotherapy, radiation, and the new technologies of targeted therapies. Oncology nurses have witnessed the dangers of treatment, including disfigurement from surgery, life-threatening sepsis from immune suppression, and residual side effects from all treatment modalities. Oncology nurses witness the physical pain and emotional grief of their patients. Many of us have held the hand of a dying patient who had fought long and hard but eventually lost his or her battle.

For most patients, the cancer journey can be a frightening and long expedition into unknown territory—feeling helpless to protect themselves against the assaults of the disease. Prior coping resources used for other life challenges may be helpful, yet cancer often requires new skills and inner resources that the patient must learn at each step within each stage of the disease (Bush, 2006). The patient, his or her family members, and the oncology nurse all are vulnerable to symptoms related to PTSD (Bush, 2009a).

Risk Factors for Post-Traumatic Stress Disorder

The probability of developing PTSD depends on variables that go beyond the actual experience of the traumatic event. Cognitive function or interpretation of the event is an important determining factor. The individual’s thought processes and values are recorded in memory, and this impacts the interpretation of the traumatic event, influencing how the trauma is internalized and remembered. Johnson (2009) differentiated between adaptive and maladaptive cognitive schemas (see Figure 5). Adaptive cognition is related to strong coping abilities, resilience, and trust. Maladaptive cognitions include feelings of vulnerability, weakness, unworthiness, and incompetence.

It would appear that the more severe the traumatic event, the more likely for the individual to develop PTSD. The level of stress, panic, and physiologic arousal present at the time of the trauma are predictors of developing PTSD (Friedman et al., 2007). Firsthand exposure to the traumatic event and fearing for one’s safety will increase the risk. In addition, however, PTSD is a com-

Adaptive Cognitions

- Positive meaning from the experience
- Resilience
- Strong coping abilities
- Trust

Maladaptive Cognitions

- Incompetence
- Intense fear
- Negative meaning from the experience
- Unworthiness
- Vulnerability
- Weakness

Figure 5. Risk Factors for Post-Traumatic Stress Disorder

Note. Based on information from Johnson, 2009.

plex illness with many contributing causes, ranging on a continuum from personal and family psychiatric illness to a history of childhood trauma or abuse, exposure to recent trauma, and avoidant coping styles (see Figure 6). For children who have experienced emotional, physical, or sexual abuse, neurobiologic circuits may be set, decreasing the threshold for psychiatric disorders such as depression and anxiety and increasing the risk of PTSD with further exposure to life stressors (Fairbank et al., 2007). Developmental stage in life will affect the meaning of the trauma to the individual. Women, like children, have an increased vulnerability to PTSD, with women experiencing the syndrome at twice the rate as men, although the overall risk of trauma is greater in the male population (Friedman et al., 2007).

Cancer-Related Risk Factors

A literature review by the NCI (2010) addressed cancer-related risk factors contributing to PTSD (see Figure 7). These included severity of disease such as bone marrow or stem cell transplantation. Patients with recent diagnosis and treatment are more vulnerable, as well as patients with recurrent or advanced disease. Duration of treatment is a risk factor for populations such as patients treated for childhood malignancies over a long period of time. The presence of disease- or treatment-related side effects and pain increases the patient’s stress and has been correlated with intrusive thoughts and re-experiencing of symptoms.

My personal risk factors for developing PTSD were numerous. I was a child of physical, emotional, and sexual abuse. Childhood trauma continued into my tender adolescent years when my parents divorced. In addition to my father abandoning the family, my mother moved us out of our neighborhood and schools to relocate to a financially feasible low-economic town at the gateway to Cape Cod. As an adolescent, my life was completely turned inside out, but I found solace in close friendships and becoming involved in school activities. As distant as

- Development life stage
- Females more vulnerable than males
- Firsthand exposure to trauma
- History of childhood emotional, physical, or sexual abuse
- Personal and/or family history of psychiatric illness
- Severity of trauma

Figure 6. Specific Risk Factors for Post-Traumatic Stress Disorder

Note. Based on information from Johnson, 2009.

my relationship had been with my parents, my relationship solidified with my siblings. I became chief cook, maid, and mother to my younger sisters. Private time and off-time to meet my own needs were minimized.

Reflection

Reflect upon this question: If you were asked what children’s story could best portray your personality, what would your reply be? For example, you may have thought of Watty Piper’s (1987) classic, *The Little Engine That Could*. Many of us can relate to the moral of the story, “I think I can. I think I can. I think I can” (p. 32).

I queried my son, and, without hesitation, he responded with *Where the Wild Things Are* by Maurice Sendak (1963). For a young boy with a wild imagination and one who never stopped in his own tracks, this was a very insightful reflection.

In one of my clinical psychology graduate courses, we were asked the very same question. My choice was easy. I was *The Giving Tree* by Shel Silverstein (1964). Many of us today may relate to this poignant story about a young boy who grows up alongside his favorite and most beloved tree. The tree provides him shade, apples to eat, a place to play and rest, and he carves his name in the trunk. For me, the story is about giving—an innate quality I have shown since childhood. As a young man, he begins to ask the tree for more than nurturance, shade, and protection. He asks the tree if he can pick its apples to sell them, and then he asks to cut its branches to build a house for his family. The tree was always happy to give what it thought would make the young man happy. As the man grows older, he asks the tree if he can cut its trunk to make himself a boat. The tree replies, “Cut down my trunk and make a boat—then you can sail away . . . and be happy” (p. 43). The man cut down its trunk, made a boat, and sailed away. Reading the story, you begin to feel that the tree was lonely and not really happy. The only thing remaining was a stump. Years later, the man (now old) returns very tired and the stump is tired, too. The tree tells the man, “I have nothing left. I am just an old stump” (p. 48). The man tells it that he just needs a quiet place to sit and rest. Well, said the tree, straightening itself up as much as a stump can do, “Come sit down and rest” (p. 49). And the man did.

The stump still provided the old man with a place to sit and rest his weary bones. And the tree was happy.

Over the many years, the tree had lost its ability to grow, nurture new leaves and fruit, and could no longer provide gifts of solace and protection from the heat of the sun. When I began to suffer from PTSD, I thought about my favorite book. Several years earlier, we had lost a large, probably 500-plus-year-old oak tree in our backyard when torrential rains softened the ground and the weight of the tree pulled up its root structure. I asked the landscaper to leave the stump of the tree in the ground and replant its roots for security. I often still sit on this stump and warm my face toward the sun. I bought a plaque to set on the stump that reads, “Set your mind on things above” (Colossians 3:2). As the fable of *The Giving Tree* brings to light the rare gift of unconditional love and selfless giving, the story demonstrates the dangers of giving too much, so much that the abundance of gifts the tree could have given have been drained of resources. And the tree was lonely.

My reason for sharing this tale is that as oncology nurses and natural caregivers, we must learn to take care of ourselves as well as our patients and those we love. There may be times when we ourselves need to be nourished and protected. As difficult as I found this my entire life, I learned that we must set boundaries before we have nothing left to give to ourselves, let alone to others. When diagnosed with PTSD, I felt like the stump of my once healthy and beautiful tree. I had no coping resources or emotional reserves to even care for my own needs. The endless trauma in my life finally caught up with me. I was stripped naked—I could not find the energy to even cope with the stressors of what was my daily life—from the continuum of dressing in the morning to commuting to work, staying focused during my work, and, above all, coming home and meeting what I then felt was the neediness of my small family. I only had two or three small branches sticking out of the stump, much like a stick person drawn with her heart beating wildly out of control. Similar to the carved heart on the dried and cracked stump, my heart was not exposed to the harsh elements of nature but instead to the harsh elements of grief.

Levine (2005) called the hardness at the edge of ourselves, not being met or held by anything soft, as

- Advanced disease
- Bone marrow or stem cell transplantation
- Duration of treatment
- Pain
- Recent diagnosis and treatment
- Recurrent disease
- Side effects from treatment or disease

Figure 7. Cancer-Related Risk Factors That Contribute to Post-Traumatic Stress Disorder

Note. Based on information from National Cancer Institute, 2010.

unattended sorrow. Levine stated that there is no greater manifestation of grief than numbness. I was finally numb, and I had allowed that numbness to deepen over the years of my life in an attempt to compartmentalize my pain. My grief was condensed like the stump of *The Giving Tree*. Levine further stated, "Feelings of loss don't go away; they go deeper. When we lose or never exercise what we need or love, we call the hard contractions in the mind and body 'suffering.' This is unattended sorrow" (p. 9). At the time I finished active cancer treatment, the sorrow that I had carried in my heart for a lifetime came seeping out of my pores. At times it felt unbearable. My young adult life was plagued with infertility treatments and loss after waiting three years after melanoma to start a family. The previous five years prior to diagnosis were life-altering. Research has identified that extreme stressors occurring prior to a traumatic incident increase the risk for PTSD.

Our young son was diagnosed with clinical depression in his freshman year of high school. Even with a year of psychological support, my husband and I made the difficult decision to send him to a therapeutic wilderness program in Utah. My father was diagnosed with dementia, and my younger sister Cindy went through a difficult divorce and was caring for three small children when she was diagnosed with breast cancer. Our stepsister was in a near-fatal car accident requiring two craniotomies. I will always remember the hardships at my father's funeral; not just related to his death, but also because of the sight of my sister two weeks postmastectomy with drains still in her chest and my stepsister in a wheelchair brought from the rehabilitation center. A year after my father's death, my sister Cindy and I moved our mother from Florida to be near us in California to care for her because she was beginning to suffer from what we now know is Alzheimer disease.

My husband had survived his bout with melanoma, diagnosed in 1998, only to have a second autoimmune muscular disease diagnosed two years later. Weekly immune globulin was ordered, and I began to give his treatments in the home. When diagnosed with cancer in 2007, our marriage was at an impasse. Was I his nurse, his mother, or his wife? I had also started a new nurse practitioner job one year prior to diagnosis. It always seemed like our lives were in turmoil even before I got a third diagnosis of cancer.

Clinical Presentation of Post-Traumatic Stress Disorder

The clinical presentation of PTSD will include a significant change in the individual's mood, affect, and behavior (see Figure 8). Research has shown that, when compared to people suffering from major depressive disorder or obsessive compulsive disorder, PTSD dem-

onstrated impairments in the person's general vitality, mental health, and social functioning. Quality of life is diminished, and the effects of PTSD have a negative impact on the body and mind. Symptoms range from irritability to high-risk behaviors, and the individual's personal, social, and occupational roles are disrupted. Individuals with chronic PTSD may carry out risk-associated behaviors such as self-mutilation or substance abuse to mask emotional pain (Johnson, 2009).

Comorbidities and Differential Diagnosis

The most common comorbidities associated with PTSD are depressive and anxiety disorders. Differential diagnosis is challenging because of overlapping symptoms. PTSD may result in depression, and premorbid depressive disorder may increase the risk of PTSD. The differential diagnosis is that re-experiencing symptoms is present only in PTSD. The sense of a foreshortened future is a common symptom of PTSD, particularly in the cancer population. Other major psychiatric diagnoses may coexist with PTSD as comorbid illnesses, but astute assessment can differentiate diagnostic criteria for generalized anxiety disorder, panic disorder, and obsessive compulsive disorder (see Figure 9).

Depression, anxiety, and PTSD can exacerbate a patient's disease-related physical symptoms such as fatigue and pain or emotional symptoms such as moodiness and irritability, among others. Research studies support the *DSM-V* inclusion of the diagnosis prolonged grief disorder (PGD). PGD has some overlapping criteria with PTSD but different criteria that will expand abnormal or ineffective grief disorders related to underlying issues of attachment and dependency (Prigerson et al., 2009).

Therapeutic Interventions and the Role of the Oncology Nurse

Nurses represent the first line of therapeutic assessment and intervention for individuals with cancer; therefore, they play a vital role in identifying psychiatric

Body and Mind

- Anger
- Anxiety disorders
- Avoidant behavior
- Chronic pain
- Depressive disorders
- High-risk behaviors
- Irritability
- Somatic complaints
- Substance abuse

Quality of Life

- Mood disturbance
- Negative impact on daily activities
- Negative interpersonal relationships
- Physical ailments
- Poor work performance
- Social impairment
- Unemployment

Figure 8. Clinical Presentation of Post-Traumatic Stress Disorder

Note. Based on information from Johnson, 2009.

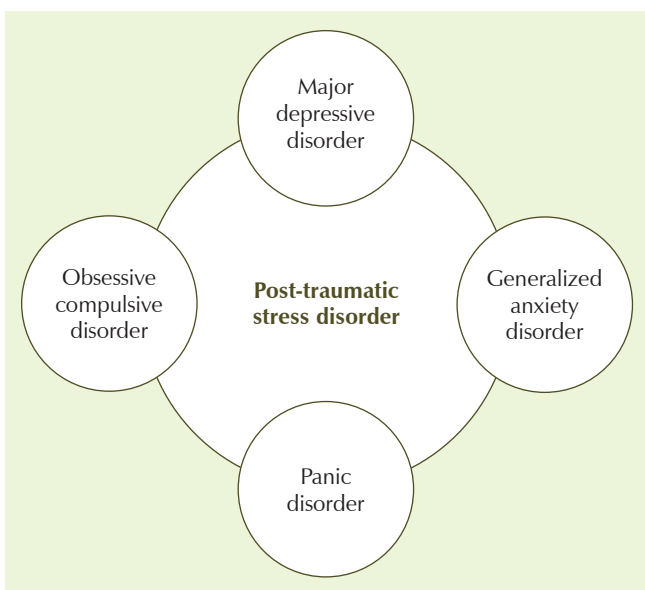


Figure 9. Comorbidities Associated With Post-Traumatic Stress Disorder

Note. Based on information from Johnson, 2009.

symptoms that include PTSD (American Cancer Society, 2009; Kwekkeboom & Seng, 2002). Basic assessment questions can be used by the general oncology nurse to screen for PTSD (Kwekkeboom & Seng, 2002). Examples include "Have you been feeling jumpy or irritable since your cancer diagnosis?" and "Have you been having nightmares about any aspect of your experience with cancer or treatment?" Oncology nurses can identify early symptoms that can trigger PTSD or comorbid psychiatric illnesses that may coexist with PTSD. Normalizing the individual's fear and anxieties and providing a safe and trusting environment will encourage patients to reach out for emotional support when needed. Suspected psychiatric problems of any kind require immediate referral for diagnostic workup. Treatment modalities for PTSD include psychotherapeutic interventions such as cognitive behavior therapy, pharmacologic management, group therapy, and integrative interventions such as yoga, acupuncture, and Reiki.

Hope, Recovery, and Healing From Post-Traumatic Stress Disorder

At this special time of being honored with the Mara Mogensen Flaherty Lectureship, I am reminded of my lifetime of blessings and love, of which my oncology nursing profession has played a major role. Many times over the last three years I worried that the hopeful, optimistic, and genuinely joyful essence of me would never return. As unique as every patient is, so is his or her journey. The responses of the patient being confronted by the illness will depend on that individual's past, present, and development stage at diagnosis.

For me, already an oncology nurse who had learned the value of life from my patients, it was the spiritual component of my journey that has been greatly influenced by three diagnoses of cancer. Slowly I came to the realization that valuing life is different than living one's life to the fullest. At midlife—if fortunate to beat these last two diagnoses, or if not, even so—I want to find my personal balance between giving and receiving, and I want to regain inner peace and comfort. Since my sudden and shocking diagnoses, I have been searching for my purpose and the meaning of my life in this vast universe.

Most of us are familiar with the touching story by Mary Stevenson, *Footprints in the Sand* (see Figure 10). Although a Christian story, the name of the Lord could easily be Yahweh, Allah, Brahma, Buddha, Krishna, or such. It is the presence of the divine and faith in our lives that comes to the forefront, particularly in our times of need.

Personally, I believe that the Lord or God is carried within each of us; within the hearts of loved ones, friends, colleagues, patients, and, for me, my students. Most of my spiritual moments have occurred during my work with patients when I have had the honor to walk beside them on the paths of their journey. I have hoped that through my presence and empathic caring I have been an additional set of footprints walking beside them,

*One night I dreamed I was walking along the beach with the Lord.
Many scenes from my life flashed across the sky.
In each scene I noticed footprints in the sand.
Sometimes there were two sets of footprints,
other times there were one set of footprints.*

*This bothered me because I noticed
that during the low periods of my life,
when I was suffering from
anguish, sorrow or defeat,
I could see only one set of footprints.*

*So I said to the Lord,
"You promised me Lord,
that if I followed you,
you would walk with me always.
But I have noticed that during
the most trying periods of my life
there have only been one
set of footprints in the sand.
Why, when I needed you most,
you have not been there for me?"*

*The Lord replied,
"The times when you have
seen only one set of footprints,
is when I carried you."*

—Mary Stevenson

Figure 10. *Footprints in the Sand*

Note. From "Footprints in the Sand," by M. Stevenson, 1936. Retrieved from <http://www.footprints-in-the-sand.com/index.php?page=Poem/Poem.php>. Copyright 1984 by Mary Stevenson. Reprinted with permission.

helping to lessen their weight. It was on the wings of my courageous patients that I hung onto tightly throughout my own cancer experience. Our patients are our greatest teachers. Finally, the calm reassurance and encouragement of my oncology caretakers carried me through my latest storms.

At initial diagnosis, the sacred beach within my heart was crowded with footprints. A silver lining of my cancer experience was bearing witness to my own eulogy while being fully present. I have never been so humbled and I felt truly blessed.

Four months prior to the one-year anniversary of my dual diagnoses, I began to feel differently. I realized that I was desperate for help from someone or somewhere that could provide me with the skills to ground myself (Ferrell et al., 2005). I was tired. I was an insomniac. I was irritable from lack of sleep and treatment-induced fatigue. I was having hot flashes that consistently made me change my clothes and take frequent showers for comfort. The aromatase inhibitors exacerbated my hot flashes. I felt hot inside and out, from head to toe, my heart included. With my fatigue and lack of hormones, I had no libido (Hawkins et al., 2009). At times, I did not even want to be touched. I was lonely and needed comfort, but I could not reach out and ask for it. I felt disconnected.

Most of my spiritual moments have occurred during my work with patients when I have had the honor to walk beside them on the paths of their journey.

I found myself at work one day confronting a friend and colleague for the first time in the many years of working together. Exasperated, she said, "You are angry and filled with rage. You are not dependable. You are not yourself anymore." That one statement stopped me in my tracks. I reflected upon my newfound identity crisis. If I was not the same me anymore, then who was I? And if my behaviors could not be forgiven for the stress that I had been under, then where should I turn?

On impulse, I voluntarily admitted myself to an inpatient facility in Arizona to seek the support I so direly felt I needed. I was strip searched on arrival. I had to go to a small window, feeling like a small child, to receive medications. I was placed on a medication for bipolar depression because this illness is genetically inherited and I have a sister with this diagnosis. I never slept an entire night because of the extrapyramidal symptoms I experienced from the new medication. I feared having a seizure and dying when in the care of strangers. Each evening, all patients had to choose a nightly group to attend. I looked at the board and reviewed the listing—12-step treatments ranging from alcohol to substance abuse, from eating disorders to codependency issues. Of course, I chose codependency although I no longer

support the concept. As we went around introducing ourselves, "Hi, I'm Nancy Jo, I'm codependent," I experienced a panic attack. I felt the room closing in on me. Why was I here? Where was the help I needed? I was lonely, emotionally exhausted, and, by the third day, although kind, no staff member had yet approached me to hear my story or individualize my care plan. It was a kind and supportive physician on the fourth day who finally saw me in clinic for evaluation. Hearing my story, he said, "You have PTSD. You do not belong here. Our institution does not offer programs for cancer survivors." He changed my antidepressants and sent me home to heal and recover with supportive family, psychotherapy, and medications.

This experience was one of the most dramatic in my life. For an individual with PTSD, a frightening and nontrusting environment exacerbates the fear and recollections of what brought him or her there in the first place. I realized then, and now, that as survivorship increases in the specialty of oncology, so must programmatic support to meet the needs of patients suffering from depression, anxiety, panic disorder, PTSD, and in the near future, PGD. Our patients deserve better than to be left out to flounder with clipped wings.

Reflection

Reflect on how many lives you touch daily in your work as an oncology nurse. As an oncology nurse, you have grown wings and, for countless patients and their families, you have become the wind beneath their wings helping them to fly.

Cancer does not define the individual. The patient facing cancer defines the experience by his or her own perspective based on variables such as personality characteristics, past coping styles, locus of control, optimism, and resiliency.

Wilson and Agaibi (2006), experts in the field of PTSD, asserted that resiliency is a determinant factor that enables some people to overcome and transform profoundly traumatic life events. These researchers stated that resiliency connotes strength and flexibility, high self-esteem, hardiness, internal locus of control, autonomy, assertiveness, and humor. For the individual who has confronted cancer, resilient characteristics such as gaining a positive sense of identity as a survivor and having the capacity to generate meaning from the cancer experience are essential for recovery and healing. A very important facet of resiliency is that it is believed to be not only an innate characteristic but also one that can be learned.

Jacob's dream in the Old Testament (Genesis 28: 10–12) speaks about a ladder that connects the Earth and the heavens. Tiny angels are going up and down the ladder—a profound symbol of support, connection, and hope. I have been surrounded by my very own angels during this journey. Some of my angels have walked

beside me, holding my hand steadily, their footprints beside mine every step of the way. A few angels have actually carried me through times of crisis and have remained patient and understanding through the continuum of my diagnosis and my PTSD. At times of distress, there often has been only one set of footprints, and I have been carried by special guardian angels—angels who I began to call my “tear catchers.”

Harriet Ward Beecher (n.d.) poignantly stated, “Tears are often the telescope through which we see far into heaven.” My angels have had patience and endurance and are strong in their footsteps, never doubting my courage or tenacity even when I doubted myself. My angels have provided unconditional love and hope. Providing trust, safety, and guidance is an innate gift of oncology nurses. I envision these angels going up and down Jacob’s ladder from heaven to Earth; I feel and see godliness in their eyes and I have felt it in their touch. Nursing angels have lifted me up from my pain and anguish and continue to do so. It is more than true when our patients tell us that they learn quickly which family members, friends, and healthcare providers will stay the course. My journey confirmed the dedication and commitment of those nurses who choose to work in oncology. Without doubt, oncology nurses stay the course. In an editorial in the *Oncology Nursing Forum*, referring to the devastating earthquake in Haiti, Assistant Editor Susan Moore, RN, MSN, ANP, AOCN®, (2010) stated, “Faced with life’s tragedies, nurses do whatever is necessary to make things better. Nurses are among any disaster’s heroes and heroines, providing assistance wherever needed” (p. 117).

I learned that cancer is truly a family experience. My husband has stood patiently beside me, putting his own emotional and physical needs behind mine. Just months short of my three-year journey, my son has remained calm during my mini-breakdowns of uncontrolled tears and he has stayed steadfast during my tantrums of frustration and low self-esteem. Lastly, my sister Cindy has supported me every step of my journey. We became so close that her family became our family. By caring for me, undoubtedly, my sister Cindy had times when she has had to relive her own painful fight against breast cancer.

Research supports that the experience of cancer may contribute to spiritual responses such as a search for meaning and self-transcendence. The search for meaning can range from asking the question, “Why me?” to searching for the meaning of your existence when confronted with a life-threatening illness. Self-transcendence is the ability to integrate a broader perspective on the meaning of life, bringing the person in touch with a force greater than the self, more powerful than the here and now. Some patients have expressed that their lives have been enriched by the cancer experience, helping them to reprioritize what is important in their lives, enhancing self-awareness, heightening an appreciation

for nature, and contributing to new coping mechanisms such as prayer, meditation, and guided imagery (O’Connor, 1998). Wilson (2006) used the framework of positive psychology to study the effects and recovery from PTSD. Transcendent trauma survivors are viewed as the gold standard of healthy adaptation. Their survivorship has demonstrated “the capacity to overcome the hurdles and obstacles placed in their way by severe trauma and have succeeded in living life fully with integrity” (Wilson, 2006, p. xxiv).

Although the experience of cancer also can contribute to spiritual distress, there can be newfound inner strength and pride in overcoming the challenges faced by diagnosis and treatment. I sum up my own survivorship with one of my treasured sayings by Joan Walsh Anglund (1967), “Every tear I ever cried, turned to pearl before it died. Every pain within me burned, turned to wisdom I have earned” (p. 19). I have learned from my journey that life’s challenges do not take away from the essence of who we are, but just the opposite—survivorship expands our potential for love, wisdom, hope, faith, and charity.

“Sometimes right back where you started from is right where you belong” (Standley, 2007b). The essence of our soul and our being does not change with cancer, but our lives can become enriched when we reflect on how very much we have been blessed with, even in the face of tragedy.

Survivorship is to outlive and outlast the challenges faced. Metaphorically, I visualize one of my favorite flowers, the rose. In the spring and summer, the rose blooms beautiful colors and emits wonderful fragrances. Each rose is as individual as each of us. What has matured and blossomed has needed tender care and attention. Roses need to be cut back; most have thorns that can pinch and sting, and in the winter months, the bush is cut down and goes into hibernation, yet still bears fruit and seeds. Throughout winter, the planted bush continues to spread its roots underground as the branches begin to grow back toward the warmth of the sun—searching and preparing for new growth.

Often we do not pay attention to the rose bush in the cold winter months when it is thorny and unattractive and appears like it is dying. We often forget to fertilize the roses and appreciate them during this time of their preparation for new growth and renewal. This metaphor can be applied to our patients and the special care required during their times of cold hibernation and quiet withdrawal. This is the most important time to care for them. Patients need the most nurturing and have a desire to be loved, even when they are thorny, unattractive, and detached.

As oncology professionals, we have learned from our patients the importance of stopping to smell the roses. Even when living a stress-filled life, I understood the value of life and health from my patients—and I have

always stopped to smell the roses. As therapy, I cut from my rose garden during the spring and summer and fill my house with the colors, fragrances, and beauty that my rose bushes generously give to me. But now my recent cancer journey has taught me that it is not enough to just stop and smell the roses; it is time now to dig my hands into the Earth, feel the soil, and plant the roses myself. It is time for me to plant new beginnings by integrating my past and regaining hope for my future. Spiritualist Ram Dass (1989) wrote, "Just as in a garden, we do not 'grow' flowers; rather we create the conditions in which flowers can grow—the conditions for healing involve faith in the possibility that healing can occur and must resonate with the deeper and wiser parts of the self where healing takes place" (p. 171). Our patients need to maintain hope every day of their lives, even at the end of life. The goals of hope may change within the context of our life cycle, but like our souls, the essence of hope remains the same.

My recovery also has made me more aware of the cycles of life and death. I now have gained an inner peace and believe that I am on the path destined for me. It is an inner peace that I hope you can all strive to find in your own lives. We must all continually strive to learn, grow, and contribute to the greater good of the lives and the world around us.

The last three years and the five previous to diagnosis have been extremely difficult. I continue to feel loss and grief for my husband's illnesses—and the grief related to the illnesses and loss that my closest friends are experiencing. My dear mother-in-law was diagnosed with stage IV breast cancer two weeks after my treatment ended and she has already suffered her first recurrence. Life is a continual challenge. The difference now is that I have greater insight and perspective on who I am and what I need to do to take care of myself so that I am once again strong enough to support those whom I love. When I feel even healthier in body and soul, I am anxious to return to my clinical work and hold the hands of patients and their loved ones. I will feel free again just as The Hollies (1969) sang, "He ain't heavy—he's my brother," and being present is what I do best. Luciano de Crescenzo (n.d.) eloquently summarizes my message of hope and healing,

"We are each of us angels with only one wing, and we can only fly by embracing one another."

To say that it is an honor to be awarded the Mara Mogensen Flaherty Lectureship is an understatement. It is the highlight of my career to be acknowledged by the ONS Foundation for my professional contributions to psychosocial oncology. My thanks to sanofi-aventis for sponsoring this valuable award in recognition of psychosocial oncology nursing care.

I dedicate my talk to my dearest friend, colleague, and mentor, Rose Mary Carroll-Johnson, MN, RN. Hopefully you all recognize her as our esteemed editor of the Oncology Nursing Forum. To me, I know her as "Rosie." We met 30 years ago in graduate school, and I have hung onto her heart and her coattails ever since. She is courageously fighting her own battle against cancer, and I am more than blessed to have her in my life.

I would be remiss if I didn't thank my family members who have provided unconditional love and support for my personal goals. My husband, Steve, himself a cancer survivor, also is a courageous survivor of two chronic muscle diseases that he has battled since he was 20 years old. He has taught me the challenges of chronic illness, its impact on quality of life, and the meaning of tenacity and courage.

My love and gratitude for my son, Derek, is unquestionable. As early as fourth grade, when I apologized for missing his classroom party because of a work obligation, he replied, "Mom, you care for sick people. That makes me proud." Throughout his personal journey of recovery from clinical depression, Derek has been an inspiration for my belief in resiliency.

My sincere gratitude to my colleagues who nominated me for this prestigious award: Rose Mary Carroll-Johnson, MN, RN, Debi Boyle, MSN, RN, Rebecca Crane-Okada, PhD, RN, and Selma Schimmel. Deep appreciation for my professional mentors: Julena Lind, PhD, Linda Sarna, DNS, RN, Stanley Rossman, MD, and my cotherapists and psychology supervisors at Counseling West and the Wellness Community®. Many thanks to the University of California, Los Angeles, School of Nursing faculty and graduate oncology students, past and present.



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