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Depression Assessment and Psychosocial Interventions for Cancer Survivors and Their Partners

Terry A. Badger, PhD, PMHCNS-BC, FAAN
2008 Mara Mogensen Flaherty Memorial Lectureship

It is an honor to be selected for the 2008 Mara Mogensen Flaherty Memorial Lectureship. I want to thank my colleagues, Ki Moore, DNSc, RN, FAAN, Karen Weihs, MD, and Chris Segrin, PhD, who nominated me, the panel who selected me, the nurses who I have been privileged to work with, and the cancer survivors and families who have taught me about the importance of caring for the whole person. I also want to thank you in the audience for allowing me to talk about the clinical and research interest of my nursing career: caring for people and their families who suffer from depression and a life-threatening or chronic illness.

The purpose of this lecture is to discuss depression, a significant mental health issue, and psychosocial interventions, defined as the activities that enable the provision of service (e.g., assessment, referral, care coordination, treatment) for cancer survivors and their partners. With the recent publication of the latest Institute of Medicine ([IOM], 2008) report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, there is a growing national recognition that many patients and their families report unmet psychosocial needs and that psychosocial care is essential. A survey by *USA Today*, Kaiser Family Foundation, and the Harvard School of Public Health (2007) found that 26% of respondents reported that their providers did not pay attention to any factors beyond their direct medical care. Psychosocial needs typically were ignored.

I believe it is time for nurses to rise to the challenge of caring for the whole person because “nurses practice from a holistic base and incorporate bio-psycho-social and spiritual aspects of health” (American Association of Colleges of Nursing, 2008). We have long recognized that attending to psychosocial needs is an integral part of quality care. I believe that nurses are ideally situated in the healthcare system to provide psychosocial interventions to patients and their families. This is our opportunity to model high-quality cancer care; together we can change practice.

Theoretical Perspectives and Background

I have a contextualist perspective to practice and research because I believe that depression in cancer cannot be understood or treated without considering the context, including the people within the context, in this case the cancer survivor and family members (Badger, 2008). This perspective grew from early in my career as an advanced practice nurse in psychiatric mental health nursing in a Veteran’s Administration (VA) mental health clinic. I was exposed to some key theories, such as family systems theories (Broderick, 1993), interpersonal relations in nursing theory (Peplau, 1995), and the diathesis-stress vulnerability theories of depression (Rohde, Lewinsohn, & Seeley, 1990). In my practice, my clients seemed to have depression and some type of life-threatening or chronic illness and their family members or partners suffered from depression as well. I use the term partner rather than family member because of the changing dynamics of the U.S. family (Segrin & Flora, 2005), with more than half of



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cancer survivors living in nontraditional households; nontraditional is defined as any household that is not a “heterosexual married couple with two children and a dog.” Partner, in my contextualist viewpoint, is defined as anyone within the survivor’s social network that is important in the survivor’s recovery, whether or not related by blood or marriage. Further, I believe that we must include these social network members when providing high-quality psychosocial cancer care.

I found daily examples documenting that stressful life events, such as cancer, were a significant risk factor for developing depressive symptoms or depression in the survivor and partner. The research supported that clinical observation (IOM, 2008). About 20%–25% of people who experience major stressful events develop depression. Depression, the most common mental health problem experienced (World Health Organization [WHO], 2008), often is called the common cold of mental illnesses. WHO reports that depression affects about 121 million people and is the second-leading cause of disability worldwide. At its worst, depression can lead to suicide, a tragic outcome associated with the loss of about 850,000 lives per year (WHO). Despite the prevalence of depression, fewer than 25% of those with depression are diagnosed or treated.

When you examine the prevalence rates for depression for those with cancer, Zabora, BrintzenhofSoc, Curbow, Hooker, & Piantadosi (2001) estimated 29%–43% of cancer survivors with 14 different types of cancer diagnoses have subclinical or clinical depression. About 20%–25% experience major depressive disorder. The rates are higher than in the general population, with about 6.5% of women and 3.3% of men in the general population suffering from major depressive disorder (National Institute of Mental Health, 2008; U.S. Department of Health and Human Services, 2000). Clearly, evidence shows that people who have cancer and depression are at risk for poorer health outcomes than those with cancer alone (Zabora et al.). Some consequences of depression or depressive symptoms include increased symptom distress, decreased ability to manage symptoms, decreased adherence to treatment, decreased ability to marshal social support, and reduced quality of life (Badger, Braden, Longman, & Mishel, 1999; Badger, Braden, Mishel & Longman, 2004; Given et al., 2004; Spiegel, 1997). Symptoms of depression have been linked to decreased immune function and, when severe and persistent, to long-term survival (Spiegel & Giese-Davis, 2003; Weihs, Enright, Simmens, & Reiss, 2000).

Cancer can be considered a relationship disease because it can cause dramatic changes in relationships, roles, and psychological health for patients and their partners (Manne et al., 2006). The systems theory concept of interdependence predicts that major events such as serious illness affect the larger family or social network, not just the individual (Broderick, 1993). Indeed, women with breast cancer often describe negative consequences of the illness on themselves and their immediate family members (Manne et al., 2003; Northouse, Templin & Mood, 2001).

Although emotions are not contagious in the traditional infectious disease paradigm, research does support that emotional states are seemingly transmitted from one person to another (Hatfield, Cacioppo, & Rapson, 1992, 1994). This phenomenon is known as emotional contagion. Theoretical accounts of emotional contagion explain that people will often “catch” the emotional states of those around them through what are thought to be largely unconscious interpersonal processes that involve mimicry and matching of social behaviors. It is plausible to as-

sume that the depression of one member of the dyad could be transmitted to, or shared by, the other member of the dyad. Studies of partners of cancer survivors support the interdependence of the survivors and partners emotional distress. Northouse, Templin, Mood, and Oberst (1998) found that partners, who are critical sources of support during the cancer experience, often suffer the same or higher levels of emotional distress as cancer survivors. In my studies with partners of breast and prostate cancer survivors, about 25% of partners reported significant depressive symptoms, which is consistent with rates found by others (Badger, Segrin, Dorros, Meek, & Lopez, 2007).

There is substantial evidence documenting the critical role social support plays in physical and psychological well-being (Badger et al., 1999, 2007; Picard, Dumont, Gagnon, & Lesard, 2005; Spiegel, 1997), especially from an intimate partner (Segrin, Badger, Dorros, Meek, & Lopez, 2007; Segrin, Badger, Meek, et al., 2006; Segrin, Badger, Sieger, Meek, & Lopez, 2006; Segrin & Flora, 2005). Social support from a significant other plays a critical role in patients’ adjustment to and coping with cancer (Chantler, Podbilewicz-Schuller & Mortimer, 2005). For example, social support is negatively associated with developing depression among women with breast cancer and positively associated with general emotional health (Finch et al., 1997). Strong evidence indicates that the partner plays a critical role in supporting the survivor through the cancer journey and partners who suffer from depression do not provide effective social support to the survivor. The research evidence supports assessing partners for depression and including them in quality psychosocial treatment.

Definitions of Depression

If I asked each of you how to define depression, you would not only be able to define what depression is, but could talk about an experience of depression in the past year. The term depression is used with almost any unhappy or sad event, from when I stepped on a scale this morning and saw my latest weight, to describing a diagnosis of a major depressive disorder. Depression has been widely written about, although the term’s many definitions contribute to the lack of understanding of the seriousness of depressive symptoms, often providing barriers to its treatment.

Styron (1990) wrote in *Darkness Visible: A Memoir of Madness* that it was “a noun with a bland tonality and lacking any magisterial presence, used indifferently to describe an economic decline or a rut in the ground, a true wimp of a word for such a major illness” (p. 37). Barsevick, Sweeney, Haney, and Chung’s (2002) definition of depression is very useful for nurses because depression is defined as the entire range of feelings and emotions expressed by individuals with cancer as they manage personal and illness-related problems. It includes normal sadness in response to loss as well as chronic, depressed emotional affect, and clinical depression that meets specific criteria for a psychiatric disorder. In clinical practice, nurses observe the full range of feelings and emotions from sadness and grief to major depressive disorder.

Depression Assessment

Our challenge is to assess for depressive symptoms that go beyond normal sadness and grief as the first step in providing psychosocial intervention. Depressive symptoms usually are

assessed using one of two methods, a clinical interview using criteria from the *Diagnostic and Statistical Manual for Mental Disorders (DSM)-IV-TR* (American Psychiatric Association, 2000) or with the many written self-report measures developed specifically to assess for emotional distress or depression. Depression is defined through the DSM-IV-TR criteria as the presence of depressed mood or loss of interest or pleasure in nearly all activities for a period of at least two weeks (see Figure 1). The individual must present with at least one of these two symptoms along with four additional symptoms that include somatic and cognitive changes from normal functioning, resulting in significant distress or impairment. In patients with cancer, we must further determine which symptoms might be a result of cancer treatment (e.g., fatigue) and which might be a result of depression (e.g., anhedonia).

The written self-report measures to assess emotional distress or depression include the well known Distress Thermometer (National Comprehensive Cancer Network, 2008) that is used in a number of cancer centers to assess for emotional distress. Emotional distress, a term associated with less stigma than depression, is defined similarly to Barsevick et al.'s (2002) definition of depression. Other measurement scales, such as the Center for Epidemiological Studies-Depression Scale (CES-D) (Radloff, 1977), Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), or the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) are widely used to assess for depression (Badger, 2005). A summary of these measurement scales and the evidence regarding their relative strengths as assessment tools can be found on the Oncology Nursing Society Web site (www.ons.org/outcomes/measures/summaries.html). Regardless of the method, the key to quality cancer care is that some assessment strategy be used routinely to assess for depression in every patient and family member or partner encounter.

As you look at the DSM-IV-TR criteria for a diagnosis of depression, think about how you might assess for depression using a clinical interview as part of your routine interactions and clinical care with patients and partners. When I am asked to interview someone, I typically introduce myself, state who I am and why I am speaking with the person (e.g., I am Dr. Badger, a colleague of X and I have been asked to speak to you). Conversations usually begin with a fairly global question "How are you doing?" or "How have you been doing since last we spoke?" conveying presence or being in that moment with the person (Stanley, 2002). I refer you to Stanley's 2002 lectureship, "The Healing Power of Presence: Respite from the Fear of Abandon-

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- Depressed mood^a
 - Anhedonia^a
 - Insomnia or hypersomnia
 - Fatigue or loss of energy
 - Significant weight or appetite change (increase or decrease)
 - Psychomotor agitation or retardation
 - Worthlessness or guilt
 - Reduced concentration, ability to think, or indecisiveness
 - Recurrent thoughts of death or suicide

^a Either of these must be present for a diagnosis of major depressive episode.

Figure 1. *Diagnostic and Statistical Manual for Mental Disorders* Symptoms of Depression

Note. Based on information from American Psychiatric Association, 2000.

ment," for an excellent discussion of presence. A critical part of presence is conveying verbally and nonverbally that you really want to know about the psychosocial dimensions of the person's life. A common myth that patients might become upset or annoyed when asked this question has not been supported. I personally have never had a survivor or partner become upset or angry because I cared enough to ask and have found that it is not long before the survivor begins to tell his or her story. As you read this sample response, which has been altered slightly to protect confidentiality, please think about the criteria for depression and how you would assess for depression.

All right I guess [sigh]. I don't seem to be doing as well as some of the others though. I [sigh] just can't seem to get it together. After chemotherapy, I just want to sit at home and do nothing . . . the first few days I am sick but then I feel guilty because the house is falling apart, I am missing work, and I never missed work. Sometimes, I don't know, I just don't know how long I can do this. I think about just stopping the chemo and just live my life whatever I have left. I just don't want to disappoint everyone but I hate this . . . all this. The other day someone made a comment about my wig. I just started crying and couldn't stop. I had to leave. I mean, look at me, I used to be beautiful. I know that sounds bad, but I really was [sob]. My husband got angry last weekend because I didn't feel like going to the movies, and we used to go. I liked movies. But I don't want to see anything. I just don't care.

This survivor's story continued and she was diagnosed with major depressive disorder, with treatment initiated for her and her partner. The survivor and her partner received antidepressants and counseling, reducing the depression, anxiety, and stress in their lives, which resulted in improved quality of life. It was the chemotherapy nurse who used her expertise to recognize the verbal and visual cues of depression and who referred her patient for additional assessment.

Other factors, such as age, culture, or gender, in addition to a life-threatening illness may influence developing depression (Osborne, Elsworth, & Hopper, 2003; Trask, 2004). For example, rates of major depressive disorder in older adults (more than 65 years of age) is about 1%, with prevalence rates around 12% when you add chronic illness. Older adults also may express depression with somatic symptoms rather than mood symptoms, in part because it is more acceptable to discuss physical complaints with your physician or nurse. Culture may influence choice of language to describe symptoms or if symptoms are discussed at all. Items on some of the self-report measures, such as "I feel blue" may have no culturally equivalent meaning in non-Western cultures. Some cultures (e.g., Hispanics) also express depression with physical complaints rather than with mood complaints because it is less stigmatizing. Men suffer from depression about half as much as women, but recent research suggests that perhaps the criteria are not sensitive to how men manifest depression. Ramirez (2007) found that when men described their depressive symptoms they often included symptoms of anger, irritability, and aggression, and would deny mood symptoms. The men emphasized that only "weak" individuals suffered from depression.

Here is a typical example of gender influences with a middle-aged partner of a cancer survivor. During several conversations, this partner responded as follows when asked how things were going.

I am doing just fine, great. I have diabetes, well the doctor says prediabetes, but it's not cancer [laughter]. No big deal. I eat too much, drink too much, and don't exercise. I try but just can't do it, I work too much. There is no major thing going on right now. . . . My brother died of cancer about a year ago. I'm sad but I just don't talk about it. My wife and I don't talk about her cancer either. My wife and I just don't talk about it. I just figure the best thing to do is just get on with life, pretend this is just one more thing along with everything else . . . I really don't do anything; don't have any friends or social life. My job is to work and take care of her. I don't go anywhere cause I feel peculiar going out and leaving her alone.

Discussions with this partner occurred during chemotherapy visits and, after several discussions, we determined that perhaps he really was experiencing some depression and anxiety symptoms and that some strategies for dealing with his symptoms were warranted. This man illustrates that depression assessment and education may take several sessions before depression is recognized and treatment initiated, including referral to a caregivers group for male partners. I think about these types of conversations that take several weeks not as failures, but as planting seeds for future growth.

Barriers to Assessment and Treatment

It is important for nurses to assess their own attitudes and beliefs about depression to provide quality care. Attitudes and beliefs about depression of patients and providers may provide barriers to assessment and treatment. A major barrier to effective assessment and intervention for depression is the belief of many providers and patients that depression is a natural reaction to the cancer diagnosis rather than a coexisting and serious condition. This myth limits identification of depression as a real condition that can be treated. From earliest history to the present, myths persist that depression is a sign of weakness, witchcraft, sin, demonic possession, an imbalance within the body, or self-caused (see Figure 2). These all can influence whether a person will discuss their symptoms, how they might explain their symptoms, or what type of treatment might be acceptable. We must determine these explanatory models before we can effectively assess for depression, determine acceptable treatment alternatives, and offer alternative viewpoints to cause and cure (Solomon, 2001). Treatment will be ineffective if the person refuses to engage in it (e.g., prescribing medications to someone who refuses to take antidepressants is a futile exercise).

Depression is

- Normal when you have cancer.
- A sign of weakness: "Pull yourself up by your bootstraps."
- Witchcraft: "Evil eye or *mal ojo*."
- Demonic possession.
- Sin.
- Imbalance within the body.
- Self-caused by behavior: "If only . . . I did or didn't do X."

Figure 2. Attitudes and Beliefs That Contribute to Not Assessing or Treating Depression

Note. Based on information from Solomon, 2001.

Another significant barrier to assessment and treatment is the reluctance of many patients to share their emotional symptoms with busy medical providers. I have heard so often the statement, "I didn't want to bother. . . ." And providers can unintentionally convey to survivors and their families that the provider does not have time or is uncomfortable talking to them about unmet psychosocial needs. Patients are very astute in reading nonverbal cues (e.g., glancing repeatedly at one's watch) or noting the quick change in topic. When primary care providers were asked the primary reason for not talking with patients about depression, the reason given was lack of knowledge, skills, and comfort with what to do once depression is identified (Passik et al., 1998). Time constraints were a secondary concern. However, time constraints are a very real practice issue which is why a team (Together Everyone Achieves More) approach to psychosocial care makes sense. All providers do not have to provide all types of care to all patients; however, knowing the range of possible treatments is essential for appropriate referral.

Psychosocial Intervention With Cancer Survivors and Partners

Depression is a highly treatable disease once it has been identified and can be effectively treated in primary care settings. Antidepressant medications and brief, structured forms of psychotherapy are effective for 80% of those affected with depression (U.S. Department of Health and Human Services, 2000).

Fulcher, Badger, Gunter, Marrs, & Reese (2008) conducted an evidenced-based summary of interventions for depression. Evidence at the highest level supports the benefit of psychoeducational and psychosocial interventions in the management of depressive symptoms during and following cancer treatment in patients with different types of cancer (Carlson & Bultz, 2003; Williams & Dale, 2006). Psychoeducational and psychosocial interventions are recommended for practice.

Psychoeducational and psychosocial interventions include cognitive behavioral therapy, patient education and information, counseling/psychotherapy, behavioral therapy, and supportive interventions. Most oncology nurses can provide the psychoeducational and psychosocial interventions of assessment, patient education, therapeutic social support, and referral, whereas interventions such as cognitive behavioral, counseling and psychotherapy, and behavioral therapy require advanced education and training. Cognitive behavior therapy is defined as any specific psychological or psychosocial intervention that is relatively brief, goal-oriented, based on learning principles of behavior change, and directed at effecting change in a specific clinical outcome (Osborn, Demoncada, & Feurstein, 2006). Counseling and psychotherapy refers to interactive verbal interventions, including nondirective, psychodynamic, existential, supportive, interpersonal, or crisis interventions. Providers and patients typically agree to a specified number of therapy sessions for cognitive behavioral and counseling and psychotherapy interventions, whereas assessment or patient education, for example, may only be one session.

The evidence is clear, however, that psychosocial interventions can decrease symptom distress, increase adherence to treatment and the ability to manage symptoms, increase the ability to marshal social support, and improve quality of life (Badger, et al., 1999; Badger, et al., 2007; Given et al., 2004; Spiegel, 1997). Despite the strong evidence that psychosocial interventions

are helpful, cancer survivors and their partners are not routinely offered such interventions and, if offered, few (less than 25%) take advantage of such programs (Greenberg, 2004).

Meyer and Mark (1995) over a decade ago recommended that alternative approaches to face-to-face treatment delivery were needed to better meet the needs of patients with cancer and their families. We need to go beyond the traditional face-to-face support group. The use of the telephone to deliver psychosocial interventions has many advantages over face-to-face formats because it removes many of the access barriers to treatment. A number of nurses have developed successful psychosocial interventions (e.g., Merle Mishel's interventions with uncertainty, Barbara and Charles Given's work with symptom management).

For the past several years, my research team has been establishing the evidence for a telephone-delivered intervention, based on interpersonal psychotherapy and cancer education. This intervention is consistent with my contextualist perspective about how depression is influenced by the one's interpersonal context and that both the survivor and partner must be included as factors for cause and cure. Our findings suggest that telephone-delivered counseling is capable of decreasing the psychological distress that often accompanies cancer and its treatment for both patients and their partners (Badger et al., 2004, 2005, 2007; Segrin et al., 2006, 2007; Segrin, Badger, Seiger, et al., 2006). Survivors and their partners had decreased depression, anxiety, and stress following the intervention. I refer you to the detailed case study published in *Oncology Nursing Forum* (Badger, Segrin, et al. 2004) for a more in-depth discussion about how this psychosocial intervention works. A growing body of evidence suggests that patients treated with telephone counseling are not only satisfied with its accessibility but their depressive and anxiety symptoms remit as early as those treated in person (Ruskin et al., 2004).

The telephone also is an excellent method for nurses to provide patient education and therapeutic support. Again, my team has found that cancer knowledge was improved and stress and anxiety decreased after receiving education via the telephone; in addition, survivors and partners reported feeling very supported. We provide the cancer survivor and partner educational materials; all available at little-to-no cost through organizations such as the National Cancer Institute, and then call at an appointed time to review the materials with the person via the telephone. The telephone provides a relatively quiet, private method to discuss patient educational materials to answer any questions and ensures that the material is reviewed at least once and provides support. In general, comments have been favorable about this teaching method. As one person stated, "I look forward to my nurse calling me to discuss my homework and answer my questions."

Conclusion

Our challenge and opportunity as nurses is to incorporate psychosocial intervention (e.g., assessment, referral, care coordination) as part of quality holistic cancer care. Many organizations, such as Oncology Nursing Society, Lance Armstrong Foundation, National Cancer Institute, National Cancer Coalition Network, Wellness Community, and American Psychosocial Oncology Society (see Figure 3), have educational materials, guidelines and toolkits available in print and on the Web to increase nurses knowledge and skills in psychosocial areas. These organizations also have educational materials written

American Cancer Society

www.cancer.org

American Psychosocial Oncology Society

www.apos-society.org

Lance Armstrong Foundation

www.livestrong.org

National Cancer Coalition Network

www.nccn.org

National Cancer Institute

www.cancer.gov

Oncology Nursing Society

www.ons.org

Wellness Communities

www.thewellnesscommunity.org

Figure 3. Web Sites of Representative Cancer Organizations

for the lay public that discuss psychosocial needs of the patient with cancer and resources to address those needs.

In each of our practices, nurse should routinely ask questions related to emotional distress as part of every patient encounter, making questions about emotional distress as normal as asking about physical symptoms. Nurses should address myths related to depression and decrease stigma by talking about depression as a common experience and a disease. Nurses can share with survivors and partners the staggering numbers of people who experience depression when living with cancer. Depression is experienced by members of all ethnic groups, cultures, and by both genders. Further, nurses can emphasize that anyone experiencing depression is not alone in the experience. All these facts can help normalize the experience for those affected.

Nurse must recognize that although not catching in the traditional infectious disease way, emotions are contagious for providers as well. For example, it is not atypical to feel sad, down, or blue after an intense emotional interaction with a patient. Nurses must develop strategies to care for our own psychological health and well-being to effectively care for others. Caring can have an emotional price. Advanced practice nurses who specialize in psycho-oncology counseling or Schwartz Center Rounds (<https://www.theschwartzcenter.org>) can be used to support oncology staff to debrief about emotionally difficult issues to prevent burnout.

Finally, I close with how I began this discussion, in that I believe nurses are the key to psychosocial intervention with cancer survivors and their partners. Together, we can change the healthcare system so that no patient with cancer or their partner reports that providers do not pay any attention to any factors beyond direct medical care. As a national team, we need to work together to enact the recommendations from the IOM report and the ONS (2008) position that psychosocial assessment be a standard component of cancer care and that each patient's psychosocial needs are documented with a plan for needed services. As nurses, we can and will make the difference in psychosocial care for cancer survivors and their partners.

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