

UNIT 8

Psychosocial Health and Well-being

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You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. ~Eleanor Roosevelt

Quick Overview

- Distress has become a more widely accepted and less embarrassing term than depression, anxiety, or other psychiatric or psychological terms (National Comprehensive Cancer Network, 2007).
- Vulnerability to emotional distress following cancer has been consistently shown to predict poorer adjustment.
- Although symptoms may overlap, it is important for nurses to recognize that depression and grief are not the same.
- Cancer patients frequently report that spirituality and religion are important in helping them to cope with and adjust to the cancer experience (Edser & May, 2007)
- The ability to find meaning and the occurrence of post traumatic growth are very individualized processes that may or may not occur over time .

INTRODUCTION

The psychological distress of dealing with temporary or permanent health effects from a diagnosis of cancer and its treatment carries a significant burden for many patients and families. Challenges related to stigma, disability, long term fatigue, chronic pain, work and leisure, and the financial costs associated with cancer treatment and management may occur in isolation or be compounded by pre-existing psychosocial issues.

This chapter is designed to enhance the oncology nurse's understanding of psychosocial and spiritual health issues among cancer patients and their families. Case studies are provided to support learning. Completion of the case studies and a review of the literature will provide nurses with:

- 1. A basic understanding of common psychological effects of cancer and the transition to survivorship. These effects include depression, grief and loss, anxiety, and Post Traumatic Stress Disorder (PTSD).**
- 2. Knowledge on the roles of spirituality, religion, and meaning-making in the transition process.**
- 3. An understanding of the concept of Post Traumatic Growth.**
- 4. Helpful tools and guiding questions to support patients and families as they begin the process of creating meaning from the cancer journey to survivorship**
- 5. Resources are provided at the end of the chapter for individuals interested in learning more about psychosocial/spiritual health and well being**

What Do Oncology Nurses Offer?

Nurses are uniquely situated to recognize distress and offer timely support to the patient and family. Oncology nurses promote continuity of care by virtue of their specialized knowledge base and skills that can holistically, and at times simultaneously, address the psychosocial, physical, and /or social concerns of the patient. For example, a nurse can change a wound dressing while discussing with the patient his fear of recurrence of cancer and its potential impact on his children and family. Oncology nurses also promote continuity of care because they work in a multidisciplinary milieu in which they can refer patients who require more specialized, in-depth assessment, or treatment to other professionals and support services.

Applying the CANO/ACIO Standards and Competencies

Reviewing and using this section in practice, the nurse will be addressing in particular the following competencies:

1. Standard Practice: Comprehensive Health Assessment Relevant Competencies
 - a. Conduct a comprehensive psychosocial, spiritual, and cultural assessment that includes the individual/family's response to cancer, main concerns, feelings, fears, goals, and understanding of prognosis
 - b. Screen for psychosocial and spiritual distress using validated tools
 - c. Explore and document the impact and meaning of illness on the individual/family and their support systems (take into account present life circumstances and view of quality of life)
 - d. Assess and respect individual/family religious and spiritual practices/resources
 - e. Assess and respect cultural influences
 - f. Assess individual/family financial, Social, and practice concerns that may impact cancer experience
 - g. Assess individual/family's mental health needs including therapies and outcomes (if relevant)
2. Standard Practice: Supportive and therapeutic relationships Relevant Competencies
 - a. Apply supportive care strategies and best practice/evidence-based psychosocial care interventions within the scope of practice to facilitate effective coping
 - b. Identify individuals/families that require supportive, psychosocial and spiritual care and refer them in a timely manner

What Happens When We Don't Meet Patients' Psychosocial Needs?

Research has shown that psychological and social stressors (e.g. depression, lack of social support, limited coping capabilities, low socio-economic status) have been associated with increased morbidity, mortality, and decreased quality of life (Adler & Page, 2008; Carroll-Johnson, Gorman, & Bush, 2006; Kielcolt-Glaser, McGuire, Robles, & Glaser, 2002). Further compounding the problem of survivorship for many patients and their families is living with

the uncertainty of recurrence which may be expressed as fear, anxiety, and/or emotional ups and downs (Gaudine, Sturge-Jacobs, & Kennedy, 2003; Mishel, 1997; Nelson, 1995). Grief and loss must also be acknowledged as a component of transitioning to survivorship. The broad array of feelings and behaviours common after a loss, such as the death of a loved one, may also be experienced in direct response to other losses such as: the loss of a breast, the loss of original hopes and dreams, loss of social support, etc.

FACT: Approximately 80% of cancer survivors may experience rates of psychological distress, anxiety, depression, and diminished quality of life similar to that of the general population, however a significant number of cancer survivors may have difficulty transitioning, and/or adjusting to the role of survivor (Alfano & Rowland, 2006)

LITERATURE REVIEW

What do we mean by psychological distress?

Distress has become a more widely accepted and less embarrassing term than depression, anxiety, or other psychiatric or psychological terms (National Comprehensive Cancer Network, 2007), within the context of cancer.

Distress has been defined as “a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and treatment (National Comprehensive Cancer Network, 2009, DIS-2.).

Did you know that 18% to 43% of cancer survivors may experience significant distress requiring professional intervention? (Vachon, Lancee, & Conway, 1990; Zabora, BrintzenhofeSzoc, & Curbow, 2001)

The experience of distress is variable ranging from sadness and a sense of feeling vulnerable to profound depression. Distress can occur at any point along the cancer continuum (NCCN, 2009). Heightened distress has been associated with negative outcomes and frequently goes unrecognized or untreated (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001).

Negative outcomes include:

- Decreased treatment adherence
- Decreased satisfaction with care
- Decreased quality of life
- Decreased survival

Depression

Depression is a disease (e.g. psychiatric mood disorder) and a collection of symptoms influenced by biological (e.g. multiple sclerosis, cancer, cardiac disease), social and interpersonal stressors (e.g. sense of belonging, social support, conflict, loneliness) (Hagerty, 1999).

It is characterized by sadness beyond that considered within the normal range of emotions and which permeates all aspects of the individual’s life (Walsh, 1998). Depression may be primary (exist alone) or secondary (associated with other disease states).

Common symptoms (DSM-IV)

Clinical depression is evidenced by the individual experiencing, for at least two weeks, a depressed mood and loss of interest or pleasure in activities usually enjoyed. In addition to these symptoms, the individual must have at least four of the common symptoms listed below:

COMMON SYMPTOMS

<p>Depressed mood Difficulty sleeping* Guilt & worthlessness Lack of interest Decreased energy* Inability to concentrate Poor appetite*</p>	<p>Psychomotor retardation or agitation Suicidal ideation Hopelessness (considered a key symptom) Decreased libido Diurnal variation</p>
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* indicates vegetative symptoms

It is sometimes suggested that the vegetative symptoms noted above be replaced with the Endicott Criteria, as the vegetative symptoms might be reflective of disease or treatment side effects.

ENDICOTT CRITERIA

<p>Social withdrawal Depressed appearance Diminished reactivity Pessimism</p>
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It is important to take into account the following RISK FACTORS when considering depression:

- Severity of illness
- Stressful life events
- Prior history of depression or family history of depression
- Medications, and
- Socio-economic pressures

The Prevalence of Depression

The prevalence of depression among survivors has been estimated to range from 0-38% for major depression and from 0-58% for depression spectrum syndromes (Massie, 2004). This wide variability may be attributed in part to how researchers define depression. Although depression is considered to be the most common mood disorder associated with cancer, it can be alleviated with appropriate and timely intervention. Unfortunately, an all too common belief held by many health care professionals is that “depression is normal for the patient” (Carroll-Johnson, Gorman & Bush, 2006, p.241).

Reflecting on your own practice you may now think you have fallen into the same belief pattern, perhaps overlooking depressive symptoms in cancer survivors for whom you provide care. You are not alone! Lack of comfort, familiarity and skill in identifying major depression is not an uncommon concern among nurses who may frequently underestimate the level of depressive symptoms among those experiencing moderate to severe depression (Valente & Saunders, 2005). Nurses frequently rely on crying, depressed mood, and vegetative symptoms such as insomnia, fatigue, anorexia, and constipation to inform their assessment. In the patient with cancer and/or survivor population such symptoms are not good indicators of depression (Carroll-Johnson, Gorman & Bush, 2006) as they may often manifest as the side effects of treatment.

Vulnerability to emotional distress following cancer has been consistently shown to predict poorer adjustment.

Symptoms of depression are more likely to be associated with the following cancers: oropharyngeal (22%-57%), pancreatic (33%-50%), breast (1.5%-46%), lung (11%-44%) (Massie, 2004). Factors negatively impacting adjustment include:

- a past history of depression,
- co-morbidities,
- low socio-economic status,
- lack of social supports,
- persistent side effects of treatment and cancer,
- coping style, and
- multiple life stressors (Alfano & Rowland, 2006)

Differentiating between Depression and Grief

Common symptoms present in both depression and grief are: intense sadness, sleep disturbance, and appetite disturbance. While clinically depressed individuals experience feelings of worthlessness and lack of self-esteem, individuals who are grieving, generally do not perceive themselves as less of a person because of the loss (Worden, 2001).

Grief

Although symptoms may overlap, it is important for nurses to recognize that depression and grief are not the same. “While the world may look poor and empty for those experiencing grief, the person feels poor and empty in depression” (Worden, 2001, p.22). It is also important to understand that in addition to experiencing grief, an individual may also have a major depressive disorder, post traumatic grief disorder or other psychiatric diagnosis.

Recent research on complicated or prolonged grief disorder (PGD) has found a set of risk factors and clinical correlates of PGD including a history of childhood separation anxiety, controlling parents, parental abuse, or death, a close kinship relationship to the deceased (e.g., parents), insecure attachment styles, marital supportiveness, and dependency and lack of preparation for the death—all suggesting that attachment issues are salient in creating a vulnerability to PGD (Prigerson et al, 2009).

In the context of a cancer experience, the survivor may be focused on her/his grief experienced as the result of illness; or the illness experience may lead to re-visiting previous unresolved grief. This might be more apt to occur if there have been any of the pre-existing issues referred to above. For example, a woman in her 40’s was diagnosed with breast cancer. The diagnosis brought back memories of her mother’s death from breast cancer when she was 17 years and that of her father’s death from colon cancer two years later. The memories triggered her to revisit the grief she experienced from their loss. A woman, who had an abusive and controlling mother and had a strong positive bond with her father who died, had great feelings of abandonment when she felt that her family, friends, and health care professionals were not being as supportive to her as she would have liked when she was going through her cancer treatment. Her early feelings of abandonment were triggered. While it was difficult to cope during treatment her abandonment and grief issues surfaced when she completed treatment and did not have the support provided through regular contact with staff during treatment.

Grief may focus on a loss in the past (loss orientation) or the present and future (restoration orientation) (Stroebe & Schut, 1995). This is also referred to as the two track model of bereavement in which track one focuses on the bereaved person’s bio-psychosocial functioning and track two concerns the individual’s ongoing relationship to the range of memories, images, thoughts, and feeling states associated with the deceased (Rubin et al, 2009).

The individual may move back and forth in an effort to confront or avoid the loss. For example, a woman may grieve the loss of her breast, imagine having it back, and recognize that it was necessary to have her breast removed in order to improve her chances of survival.

Grief may be immediate, delayed, or chronic. One might also experience anticipatory grief at the thought of death. Survivors dealing with a diagnosis of advanced or metastatic disease may grieve for their life as they had known it and may grieve for what they may not experience in the future if they die of their disease, for example not being able to see a child graduate, get married, or have a child. For some survivors, even with a good prognosis, there may be an experience of grief as they feel the “death of a dream” of life as they may have anticipated it.

Nurses should keep in mind that not all individuals experience the same intensity of grief in response to the current diagnosis or past losses which may be triggered while dealing with survivorship. There is no right or wrong way, nurses must, therefore, take care not to stereotype the grief response of patients or family members. Our personal values and beliefs may influence our interpretation of another individual’s grief.

Anxiety

Anxiety is an emotional or physiological response to known or unknown causes that may range from a normal reaction to extreme dysfunction (American Psychiatric Association, 2000)

Anxiety is a broad term referring to a group of illnesses including

- generalized anxiety disorders (GAD),
- phobias,
- panic disorders,
- post traumatic stress disorder (PTSD), and
- obsessive-compulsive disorders (OCD).

GAD has been defined as an “uncontrollable disposition to worry about one’s welfare and that of one’s immediate kin” (Akiskal, 2007).

Anxiety in cancer survivors is attributed to the treatment experience and its associated adverse effects (Amir & Ramati, 2002) and /or the fear of recurrence (Vachon et al, 1989, 1990, 1991; Sanson-Fisher, 2000). Anxiety is sometimes difficult to assess in the cancer population. Stark and colleagues (2002) found that 48% of a sample population with a variety of cancer diagnoses had an anxiety disorder when assessed by questionnaire. However, when reassessed by diagnostic interview only 18% of the group fulfilled the criteria for anxiety disorders. (For further discussion on anxiety and fear of recurrence see Unit 4: Living with the Risk of Recurrence).

Post Traumatic Stress Disorder

Post traumatic stress disorder (PTSD) occurs when an individual is “unable to reconcile the shock of a traumatic event with core beliefs about one’s self and the world” (Jim & Jacobsen, 2008, p.414).

As the brain becomes overwhelmed with the information (thoughts, memories, and images) from the traumatic event core beliefs (e.g. people are innately good, self in control, self as invulnerable to death or disease, the world as just) are shattered. Symptoms emerge out of the struggle to integrate trauma related information with core beliefs and are believed to initially serve an adaptive function to help integrate the impact of cancer (Creamer, Burgess, & Pattison, 1992; Horowitz, 1992). For example:

- intrusive thoughts (e.g. involuntary, recurrent or distressing thoughts, or dreams about the cancer) help maintain cancer-related information in active memory for cognitive processing and integration
- avoidant behaviors (e.g. emotional numbness, efforts to suppress, or avoid cancer reminders) keep threatening thoughts out of consciousness to regulate against emotional distress
- a state of hyper-vigilance over physical symptoms maintains a state of watchfulness and preparedness for signs of advancing disease and trouble

The movement back and forth between intrusive memories and avoidance are theorized to be normative efforts to process the traumatic information, make sense of it and integrate it into existing beliefs. When integration fails and movement between memories and avoidance becomes chronic (i.e. symptoms persist more than one month), the individual is said to be experiencing PTSD (American Psychiatric Association, 2000).

It is estimated that 16% to 28% of cancer survivors experience intrusive thoughts following treatment completion and 15% to 34% experience high levels of avoidance after treatment (Jim & Jacobsen, 2008).

A study of long-term breast cancer survivors found that 18% of women had full PTSD and 58% experienced partial PTSD (two out of three PTSD symptom groups) (Amir & Ramati, 2002). Women who were the least ill when receiving chemotherapy were more at risk of PTSD symptoms when examined up to 60-months after treatment. The authors of the study hypothesized that a diagnosis of an early cancer stage and the healthier a woman’s perception of herself, the more difficulty she had in accepting the need for chemotherapy (Amir & Ramati, 2002). Symptoms of post traumatic stress have been associated with greater depression symptoms and decreased quality of life.

Experiencing a diagnosis of cancer, investigational work-ups, and/or treatment may also lead to patients re-experiencing trauma from the past such as sexual abuse. A recent Canadian study using regional data from Manitoba and Saskatchewan drawn from the 2005 Canadian Community Health Survey found childhood sexual abuse was associated with 49% higher odds of developing cancer when adjusted for age, sex, and race. The odds were 47% increased when adjusted for the risk factors of childhood stressors, adult health behaviors, and adult socio-economic status (Fuller-Thomson & Brennenstuhl, 2009).

Spirituality and Survivorship (adapted from Vachon 2008a)

Spirituality involves both faith and meaning (Breitbart, 2002), an attempt to make contact with or become aware of the “deep knowing” of our being (Cunningham, 2002).

Spirituality has been defined as “the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.” (Puchalski et al, 2009).

This is often expressed as a relationship with God, but it can be about nature, art, music, family, or community—whatever beliefs and values give a person a sense of meaning and purpose in life”(Puchalski & Romer, 2000,p.129). It may emerge from religious belief or it may have no relationship at all to organized religion. Although universal consensus does not exist about a precise definition of spirituality, commonalities among the various definitions can be found, including ways to find connectedness, direction, transcendence, meaning, and purpose (Reynolds, 2006).

Religion is an expression of spirituality and can be understood as the values, beliefs, and practices that people adopt to meet spiritual needs (Taylor, 2006; Highfield, 2000). Religion is defined as an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent God, higher power, or ultimate truth or reality (Koenig, McCullough, Larson, 2001).

Cancer patients frequently report that spirituality and religion are important in helping them to cope with and adjust to the cancer experience (Edser & May, 2007)

A meta-analysis of fifteen qualitative studies of women with breast cancer from ethnically and culturally diverse groups including Asian American, Aboriginal, Hispanic, and African American women (Howard, Balneaves, Bottorff, 2007) found that spirituality was an important theme. Reliance upon reflection and spirituality appeared to increase when cancer entered these women’s lives, as illustrated by a greater reliance on prayer, meditation, church attendance, and consultation with spiritual leaders. Spirituality played a significant part in helping women deal with their thoughts of mortality, and helped them cope. In Edser and

May's study (2007) of community cancer support group participants, associations were noted among self-help attitudes, proactive self help, and spirituality. Spirituality was reported to be more than just a coping mechanism, but an active, dynamic response and a positive psychological outcome. They note that it is the integration of spiritual life that is the crucial variable in assessing spirituality and argue for a conceptualization of spirituality as a "will to meaning."

Some cancer survivors find their disease results in spiritual transformation. Hirshberg and Barasch (1995) noted that some type of spiritual experience or awakening was common to long-term survivors diagnosed with incurable disease and who had exceeded their initial prognosis of survival time.

Meaning-making

The process of meaning making is a very individualized process. It is unknown when or how quickly people reach a sense of meaning in the aftermath of cancer.

Meaning-making is the ability to find a sense of order and purpose in life in the aftermath of a life threatening event (Park & Folkman, 1997; Park, 2010; Taylor, 1995; Thompson & Janigian, 1988).

- o A sense of order in life derives from deeply held beliefs about the controllability, predictability, and fairness in the world (Janoff-Bulman, 1989, 1992).
- o A sense of purpose in life derives from having important goals that directs one's behaviours and actions (Park & Folkman, 1997; Thompson & Janigian, 1988).

Today's medical and technological advances are making it possible for more people to live longer with cancer (Canadian Cancer Society, 2009). However, survival without purpose in living can exacerbate psychological suffering. For many, the cancer experience forces an abrupt confrontation with one's mortality and other related existential issues (Leung & Esplen, 2010; Lovgren, Hamberg, & Tishelman, 2010; Sand, Olsson, & Strang, 2009). Having a sense of meaning in life is important for cancer survivors because the lack of meaning has been associated with interference with the ability to cope with cancer treatment; block re-engagement in life, increase a sense of demoralization, futility, and powerlessness; and increase suicidal ideation and desire for hastened death (Breitbart, Rosenfeld, Pessin, et al., 2000; Kissane, Clarke, & Street, 2001; McClain, Rosenfeld, & Breitbart, 2003; Wilson, Chochinov, McPherson, C.J., et al., 2007). Having a sense of meaning has also been shown to buffer the physical adverse effects from cancer-related symptoms such as pain and fatigue (Barkwell, 1991; Lundstrom, Furst, Friedrichsen, & Strang, 2009; Simonelli, Fowler, Maxwell, & Anderson, 2008; Thompson, 2007).

Cancer survivors enter into a constant struggle to balance a new reality characterized by an acute awareness of the fragility of life and the threat of imminent death (Halstead & Hull, 2001; La Cour, Johannessen, & Josephsson, 2009; Sand, Ilsson, & Strang, 2009).

The emotionally and intellectually challenging process of searching for meaning is considered necessary to reconstruct a life schema that can restore a sense of equilibrium (Park & Folkman, 1997; Taylor, 2000; Thompson & Janigian, 1988). However, there is great variability in the prevalence and pattern of searching for meaning (Kernan & Lepore, 2009). The ability to find meaning does not always lead to an end to distress, but can lead to a more balanced perspective of life that positive and negative aspects can co-exist in the aftermath of cancer (Folkman, 1997; Folkman & Greer, 2000; Kagawa-Singer, 1993).

During the search for meaning, thoughts, feelings, and behaviors may be weighted heavily by concerns about one's mortality and uncertainty about the future (Lee, et al., 2004; Sand, et al., 2009; Weisman & Worden, 1976-77). In addition, individuals may feel a sense of disintegration or disconnect with oneself and with others (Mount, Boston, & Cohen, 2007). Individuals may become immobilized with regards to caring for their self, or lack the motivation to participate in social activities with family and friends.

Over time, individuals learn to balance "living with a new normal" in the face of future uncertainty (Kvåle, 2007; Sand, Ollson & Strang, 2009). Individuals may retain a sense of integrity and self-worth but accept a more vulnerable self, and pursue personally relevant goals knowing that the world is less predictable and less controllable. Many cancer survivors become more purposeful and decisive in their behaviors for example, participating only in activities that they want to not because they are expected to (Lovgren et al, 2010).

Research is still under way to understand how individuals make meaning of their cancer experience to result in psychological adjustment and adaptation. However, studies have consistently found that patients benefited from engaging in supportive social networks, environments, or activities that facilitate self-disclosure and self reflection (Neimeyer, 2004). Other strategies that have been found to be beneficial to help individuals begin to find meaning in their situation is to help patients identify realistic, short term, achievable goals, or to focus on finding something of value in the present moment. One such strategy is the use of the Meaning-Making Intervention (see Appendix 1).

Post Traumatic Growth

Post-traumatic growth in the context of cancer is a burgeoning new concept that has emerged over the last three decades (Jim & Jacobsen, 2008).

Post traumatic growth (PTG) has been defined as the “positive psychological change experienced as a result of the struggle with highly challenging life circumstances” (Tedeschi & Calhoun, 2004).

For PTG to occur the individual must have been exposed to an ‘extremely undesirable event’, have time to process and recover from the event and make meaning from the experience (Bellizzi, 2004). Individuals are able to change the meaning of the traumatic event to maintain positive beliefs about the self and world within which they live.

Post traumatic growth has been reported in three specific life domains among cancer survivors:

Commonly Reported Benefits of Cancer (Jim & Jacobsen, 2008, p.416)

Social resources	Deeper love for spouse and family Improved relationships with family & friends Increased time and effort invested in relationships
Personal resources	Better outlook on life Greater satisfaction with religion Increased compassion, sympathy, and more concern for others
Coping skills	Greater acceptance of circumstances Learning to take things as they come More effective coping with stress

Post traumatic growth is associated with the survivor’s perceived threat of death (Lechner, Zakowski, Antoni, et al 2003; Cordova, Cunningham, Carlson, et al, 2001), concerns about recurrence (Bower, Meyerowitz, Desmond, et al 2005), and perceived stressfulness of cancer (Sears, Stanton & Danoff-Burg, 2003; Cordova, Gliese-Davis, Golant, et al, 2007). While perceived threat is required to support growth too much may overwhelm the cancer survivor’s impeding growth.

The most frequently identified predictors of PTG in the research literature include:

- younger age
- ethnic and/or visible minorities
- perceived social support
- greater emotional and cognitive processing
- positive reframing (Jim & Jacobsen, 2008)

FACILITATING A SYSTEMATIC ASSESSMENT

Screening and assessment

The aim of screening is to distinguish those individuals who probably have psychosocial distress and offer help where help is wanted from those who are coping as well as can be expected given their particular situation.

When a reliable screening tool has been used and significant clinical psychological distress identified, it should be followed by a more thorough diagnostic evaluation or assessment to accurately determine if clinical depression is present. If you are unsure if the patient or family member is experiencing depression or significant distress do not hesitate to refer to a professional (e.g. a member of the psychosocial oncology team such as Advanced Practice Nurses, psychologists, psychiatrists, chaplains, or social workers) for further assessment.

Cross-cultural perspectives in psychosocial oncology

Culture significantly contributes to

- the beliefs and attitudes held about the meaning of health, illness, and cancer
- how an individual understands the experience with cancer
- what and how information is communicated among family members as well as with health professionals
- decision-making patterns that affect their health and way of life.

In this era of increasing immigration and globalization of the world, it is important to be aware of cross-cultural and intra-cultural differences. The health care provider is in a unique position to learn about how culture may influence a patient's psychological response to their experience with cancer, and subsequently enhance the effectiveness of interventions by offering culturally sensitive care.

Screening for distress

The National Comprehensive Cancer Network Distress Management Panel published guidelines in 2007 that include the use of the Distress Thermometer tool and its accompanying problem list (NCCN,2007). Tools such as this have made it easier to screen patients for distress arising from emotional, spiritual, or religious concerns, family or practical issues, or physical problems. It is now proposed as the 6th vital sign (Canadian Partnership Against Cancer [CPAC]). To date, only 36.5% of Canadian cancer centers screen for distress (Vodermaier & Linden, 2008). Consensus-based guidelines developed by the Distress Management Panel of NCCN recommend screening all patients regularly for psychosocial distress as a part of routine cancer care including follow up care (Distress Management Clinical Practice Guidelines, 2003). A Pan-Canadian initiative, CPAC (Canadian Partnership Against Cancer), is currently underway in 5 sites across Canada to evaluate a standardized approach to screening for distress. Under the auspices of CPAC, the following tools are being used: Distress Thermometer, Edmonton Screening Assessment System (ESAS), and the Canadian Problem Checklist.

Assessment

Differentiating between Depression and Grief

DEPRESSION	GRIEF
<p>Intense sadness for at least 14 days, which persists over time</p> <p>Sleep disturbance</p> <p>Loss of appetite</p> <p>Guilt (general overall sense of)</p>	<p>Intense sadness may come and go in waves</p> <p>Sleep disturbance</p> <p>Loss of appetite</p> <p>Guilt (related to specific aspect of loss rather than overall sense of)</p>
<p>Worthlessness (lack of self esteem)</p> <p>Disturbed body image</p> <p>Hopelessness</p> <p>Finds no pleasure in any aspect of life</p> <p>Active desire for early death</p> <p>Thoughts of suicide</p>	<p>Usually normal self esteem and sense of worth</p> <p>Usually normal body image</p> <p>Can still experience some pleasure in life (e.g. visits from grandchildren)</p> <p>Maintains hope for some aspects of life</p> <p>Can work through some issues</p> <p>Social withdrawal usually temporary</p> <p>Yearning for the deceased</p>

Factors that influence the mourning process (how one works through grief) include:

- who the person was in relationship to the bereaved,
- nature of the relationship,
- how the individual died,
- prior experiences of loss,
- personal characteristics (e.g. age, gender, coping style, beliefs and values),
- social (e.g. support network, role, religion/spirituality),
- life stressors (e.g. financial burden) (Worden, 2001),
- attachment issues,
- early childhood issues of abuse, attachment, and loss (Prigerson et al, 2009),
- the illness and death experience of the person who died and how this relates to the survivor's present and anticipated experience.

Symptoms of anxiety include

- arousal,
- vigilance,
- tension,
- irritability,
- non-restful sleep, and
- gastro-intestinal disorders,
- Anxious patients may also have great difficulty in anticipating or dealing with chemotherapy, radiotherapy, hormonal manipulation, or other therapies.

Increased risk factors for PTSD among cancer survivors (Amir & Ramati, 2002; Jim & Jacobsen, 2008)

- Being female,
- Younger,
- Less educated,
- Having a lower income,
- Fewer social and emotional supports,
- A prior history of trauma, and
- Difficult interactions with medical staff.

Questions to Explore Meaning and Spirituality in Cancer Survivors (Vachon, 2008a)

1. What gives this person's life meaning?
2. Is the individual questioning the meaning of her/his life?
3. How are previous beliefs either sustaining them or causing them challenges during their cancer or survivorship experience?
4. What are the person's values and how might they be affected by the diagnosis?
5. What are the person's goals in life and how will cancer affect these goals?
6. Is the person interconnected with others and how are these relationships being affected?
7. What is happening to the person's sense of self, self image, self esteem, and ability to perform usual roles in life?
8. Does the sense of meaning come from spiritual roots? Do they serve as a source of support or stress? Do they have any important religious or spiritual beliefs?

PRIORITY CONTENT FOR PATIENT TEACHING ...

Inform patients and family that:

- Feelings of sadness, depression, or anxiety are common when someone is affected by cancer
- While most individuals are able to manage or cope well, others may have difficulty with the ability to cope and make decisions related to their diagnosis and treatment
- Warn patients that medications such as steroids may cause unexpected psychological symptoms such as anxiety, angry outbursts, feelings of depression, and tearful outbursts
- If they experience any of the following symptoms, then it is important to report them to the nurse or other health team member:
 - o Heart palpitations, sweating, dizziness,
 - o Fear of losing control, fears about the future,
 - o Persistent worry, recurrent thoughts about diagnosis and treatment
 - o Difficulty concentrating,
 - o Change in behavior, functioning, roles,
 - o Three of the following six physical symptoms associated with GAD:
 - Restlessness
 - Concentration difficulties
 - Easily fatigued
 - Irritability
 - Muscle tension
 - Sleep disturbance
- There are ways to manage their symptoms and there are resources available for them
- There will be good days and there will be bad days, but personally fulfilling moments can co-occur alongside the distressing side of living with cancer (Folkman & Greer, 2000).

Your role as an oncology nurse

- Nurses are available to help survivors find meaning in their situation
- Ask questions, e.g. “You seem worried today, have you been feeling more anxious lately?”
- Use life narrative approach that provides a way to view life from another vantage point and reduces distress levels
 - o Ask “Can you tell me your story, what is important to you?” offers a way to share personal emotions and feelings with you (sometimes family) (Neimeyer, 2004)
 - o Keep a personal journal to chronicle what has happened, what is happening, and record thoughts about what may happen,
 - o Review past photos of oneself throughout the cancer journey that become a testament of the person’s strengths and capacities to arrive at where they are currently,
 - o Write a letter to oneself to motivate and be one’s own cheerleader. .
 - o Use the lifeline exercise and offer to review it with the patient (see Appendix 1).
- Act as a facilitator: assists the person to put their thoughts and feelings about what is happening to them into words. You facilitate this process of adjustment through your caring and listening.
- Offer information and counseling to family members; inform the family where they can get assistance at any point.
 - o For Depression: It is sometimes difficult to decide when to refer for depression because it is normal to have some feelings of normal sadness in response to a diagnosis of depression. A rule of thumb is that if this sadness persists beyond two weeks, health care professionals should suspect depression and treat aggressively, especially if core symptoms of depression are present. These include helplessness, hopelessness, poor self-esteem, feelings of guilt, or worthlessness, and suicidal ideation (Lovejoy et al, 2000; Bronheim et al, 1998; Vachon, 2006)
 - o For Grief Work: If nurses feel that patients are spending a lot of time discussing the losses they are experiencing as a result of their diagnosis or treatment, including the loss of fertility, then it is appropriate to refer the person to a mental health practitioner.

If survivors would like to spend time discussing feelings related to previous losses, such as a mother’s death from cancer when one is now facing the diagnosis, then it might be helpful to help the patient to discuss the person who died.

A helpful exercise for people who are having trouble with unresolved issues with grief is to suggest they write a letter to the deceased expressing unresolved feelings, regrets, unexpressed feelings, then get a new piece of paper, empty one’s mind and let the deceased write back to them. If a person has no belief in an afterlife, then it can be suggested that she/he imagine what the deceased would say.

Case example to support creation of meaning from the cancer experience

J.C. is a 52-year-old single woman who was referred for crisis intervention because she was not coping as well as expected following her diagnosis and treatment for early ovarian and uterine cancers. As a survivor, she felt she had coped well during her treatment but less so now. Since she seemed to have many questions about her diagnosis she was encouraged to take some time to think, gather information about her diagnosis and undertake the lifeline exercise reflecting on its meaning at this point in her life (see Appendix 1 on Meaning-Making Intervention for information about the lifeline).

She returned quite surprised to have “begun to connect the dots”. When she was 22 J.C. had a mastectomy and implants for large benign breast cysts. She did not feel she understood what was happening at that time nor did she have any supports thus she was left to deal with the situation on her own. For at least 20 years after that time she engaged in self destructive behavior. With the help of a psychiatrist she was able to see that her behavior and feelings were reflective of PTSD. She stopped her destructive behaviour with this insight. Her diagnosis of gynecological cancers was a shock. She had gone for a hysterectomy for what was perceived to be a benign condition. When she found she had cancer she was quickly referred to a cancer centre. Her oncologist mentioned that more surgery might be indicated for staging purposes. All she could think of was “no more surgery”. She got through her treatment with the help of family and friends. Doing the lifeline exercise allowed her to see how this surgery had reactivated the earlier issues. She was unconscious of the connection until she began the exercise. She was able to reflect upon how she had opened to help at this point in a way she never had before and how she took control over the aspects of her disease she could control. She was pleased to re-evaluate her response to treatment using the concept of post traumatic growth (approval for inclusion of this personal story has been given by the patient).

Learning Activities: Case Studies

1. R.J.’s Story

R.J. is a 50-year-old male diagnosed with Stage II prostate cancer two years ago. He declined a radical prostatectomy at that time opting for radiation brachytherapy (radioactive seeding). His wife expressed concerns after hearing him comment “I would rather die than wear a diaper!”

R.J. has been married for 25 years and is the father of two adult sons, 19 and 21 years. Both boys live with their parents. They were unaware that their father had cancer until 3 months ago. R.J.’s parents are both deceased (within the past 5 years) – his mother as a result of breast cancer at age 70 and his father from prostate cancer at 78 years of age. R.J. has a brother 53 and a sister 57. His sister was diagnosed with breast cancer at 50 (Ductal Carcinoma in Situ). She is currently in good health. R.J. continues to work as an IT specialist managing a staff of 38 for a large advertising/public relations firm.

Recently R.J. and his wife were in clinic for follow-up. While he was out of the room his wife mentioned that R.J. continues to remain uncommunicative about his cancer experience and at times appears ‘distant’ and ‘cold’. Lately he has begun purchasing what he refers to as ‘toys’ without any discussion. His most recent acquisitions included a red BMW convertible and a Harley Davidson. When she questioned him about the purchases he responded with “what difference does it make. Remember what the urologist told me – ‘you will likely die of cancer not old age!’ I may as well begin enjoying myself while I can.” (While her memory of this comment is unclear, R.J. is adamant the oncologist made this statement). Feelings of hopelessness, lack of self worth, and low self esteem continue.

1. What possible psychosocial concerns are occurring?
2. How would you begin to explore R.J.’s loss for a future?
3. What intervention(s) would you consider and why?

2. J.M.’s story

J.M. is a 27-year-old woman with multiple myeloma undergoing chemotherapy. Usually talkative and social, she has recently become quiet and emotionally fragile. Her boyfriend of three years broke up with her after she was admitted for treatment. In researching the disease on the internet, she has become overwhelmed with the poor prognosis. In addition, the patient across the hall died last night, and she overheard the family crying. In conversation with the nurse, she said “I hate it here. I just don’t know why all this is happening to me. We were talking of marriage. We wanted to buy a home on the lake. I wanted kids. Now I’m told that even if I survive, the chemo will leave me sterile. Maybe it would be better if I just died quickly like that guy.”

Some questions to ask on this case might be:

1. Is J.M. spiritual? How would you find out or open the topic of conversation with her?
2. What spiritual issues are being expressed here?
3. What is this person’s picture of life?
4. How would you respond to this patient?

Discussion about Cases

1. RJ’s Story

- What possible psychosocial concerns are occurring? Examples may include the following and should not be considered all inclusive:
 - grief (associated with loss, e.g., future)
 - body image issues (e.g. sense of masculinity, manliness, sexuality)
 - psychological distress
 - challenges adjusting to living with cancer (e.g., meaning, purpose, uncertainty/fear)

- What intervention(s) would you consider and why?
 - Screening for distress may be a helpful first step (e.g., Distress Thermometer, ESAS)
 - a. Assess level of distress and determine the need for specialist intervention (e.g. referral to member of the psychosocial oncology team)
 - b. If ESAS score is 0-4, nurse can work with RJ
 - Try out the meaning making intervention
 - Assess RJ's wife for emotional/psychological distress
- Consider trying out the three basic skills to help in moving patients through the dark journeys:
 - a. Attending to feelings — Ask survivors to name the dark feelings and not judge them as good or bad but simply present.
 - b. Befriending Feelings — Teach to tolerate and accept feelings by breathing through them. Breathing, relaxation exercises, meditation and prayer examples of strategies.
 - c. Surrendering to the suffering — Evokes wisdom, compassion & courage. Worst form of despair happens when survivors feel that pain was purposeless (Platek, 2008)
- May want to consider exploring RJ's understanding of cancer and its meaning for him.
 - o How does he see his future unfolding
When he looks in the mirror, who does he see

2. J.M.'s Story

1. Offering a statement that reflects how she is feeling may open the door to further communication: For example, you could say, "You have been through so much lately. Life is unfair and you feel like giving up. But you are still here. What keeps you going? What do you believe in that continues to give you strength? "

2. The loss of connection to her boy friend of three years and the loss to social connections (if she is less talkative and isolated), and loss of connection to herself (i.e. not recognizing who she is anymore given that her future plans have been uprooted). Explore any unexpressed anger and normalize this feeling, give appropriate outlet (e.g. writing a letter, journaling, audiotaping, art, etc)

3. Ask JM to describe further how she had envisioned her life to unfold. What has she lost? what can she retain from her hopes and dreams? Use the lifeline exercise with her.

Additional Resources

American Psychosocial Oncology Society <http://www.apos-society.org> 4 free lectures on using the Distress Thermometer

Canadian Association of Psychosocial Oncology: <http://www.capo.ca/eng/index.asp>

Canadian Mental Health Association: <http://www.cmha.ca/bins/index.asp>

Canadian Partnership Against Cancer:

http://www.partnershipagainstcancer.ca/progress2009_release

Cancer Net: <http://www.cancer.net/patient/Survivorship>

Lance Armstrong Foundation:

<http://www.livestrong.org/site/c.khLXK1PxHmF/b.2660611/k.BCED/Home.htm>

National Cancer Institute: <http://www.cancer.gov/newscenter/benchmarks-vol6-issue2>

National Coalition for Cancer Survivorship: <http://www.canceradvocacy.org/>

Princess Margaret Hospital Breast Cancer Survivorship Program: <http://www.survivorship.ca/>

References

Adler, N., & Page, A. (2008). *Cancer Care for the Whole Patient: Meeting psychosocial health needs*. Washington: National Academies Press.

Akiskal, H. (2007). Towards a definition of general anxiety disorder as an anxious temperament type. *Acta Psychiatrica Scandinavia* 98(s393), 66-73.

Alfano, C.M. & Rowland, J.H. (2006). Recovery issues in cancer survivorship: A new challenge for supportive care. *Cancer Journal*, 12(5), 432-443.

American Psychiatric Association. (2000). *Quick Reference to the Diagnostic Criteria from DSM-IV-TR*. Washington, DC: American Psychiatric Association.

Amir M, & Ramati A. (2002). Post-traumatic symptoms, emotional distress and quality of life in long-term survivors of breast cancer: a preliminary research. *Journal of Anxiety Disorders* 2002;16(2):195-206.

Barkwell, D.P. (1991). Ascribed meaning: A critical factor in coping and pain attenuation inpatients with cancer-related pain. *Journal of Palliative Care*, 7(3), 5-14.

Bellizzi, K. (2004). Expressions of generativity and posttraumatic growth in adult cancer survivors. *Aging and Human Development* 58(4), 267-287

Bower, J., Meyerowitz, B., Desmond, K., et al. (2005). Perceptions of positive meaning and vulnerability following breast cancer: predictors and outcomes among long-term breast cancer survivors. *Annals of Behavioral Medicine* 29, 236-245.

Breitbart, W., Rosenfeld, B., Pessin, H., et al. (2000) Depression, hopelessness, and desire for hastened death in terminally ill cancer patients. *Journal of the American Medical Association*, 284, 2907-2911.

Breitbart W. (2002) Spirituality and meaning in supportive care: spirituality-and-meaning-centered group psychotherapy interventions in advanced cancer. *Support Care Cancer*. 10: 272-280.

Bronheim HE, et al. The Academy of Psychosomatic Medicine practice guidelines for psychiatric consultation in the general medical setting. *Psychosomatics* 1998;39(4):S8–30.

Canadian Cancer Society/ National Cancer Institute of Canada. (2009). *Canadian Cancer Statistics*. Toronto, Canada.

Carroll-Johnson, R., Gorman, L., & Bush, N. (2006). *Psychosocial Nursing Care: along the cancer continuum* (2 ed.). Pittsburgh: Oncology Nursing Society.

Cordova, M., Cunningham, L., Carlson, C., et al. (2001). Posttraumatic growth following breast cancer: a controlled comparison. *Health Psychology* 20, 176-185.

Cordova, M., Gliese-Davis, J., Golant, M., et al. (2007). Breast cancer as traumatic: posttraumatic stress and posttraumatic growth. *Journal of Clinical Psychology in Medical Settings* 14, 308-319.

Creamer, M., Burgess, P., & Pattison, P. (1992) Reaction to trauma: A cognitive processing model. *Journal of Abnormal Psychology*, 101, 452-459.

Cunningham AJ. *Bringing spirituality into your healing journey*. Toronto: Key Porter Books Ltd; 2002.

Distress management clinical practice guidelines in oncology. *Journal of National Comprehensive Cancer Network* 2003;1(3):344-74.

Edser SJ, May CG. (2007) Spiritual life after cancer: connectedness and the will to meaning as an expression of self-help. *Journal of Psychosocial Oncology*, 25:67-85.

Fallowfield, L., Ratcliffe, D., Jenkins, V., & Saul, J. (2001). Psychiatric morbidity and its recognition by doctors in patients with cancer. *British Journal of Cancer*, 84, 1011-1015.

Folkman, S. (1997) Positive psychological states and coping with severe stress. *Social Science and Medicine*, 45, 1207-1221.

Folkman, S. & Greer, S. (2000) Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. *Psycho-Oncology*, 9, 11-19.

Fuller-Thomson, E., and Brennenstuhl, S. (2009). Making a link between childhood sexual abuse and cancer: Results from a regional representative survey. *Cancer*, 115(14), 3341-3350.

Gaudine, A., Sturge-Jacobs, M., & Kennedy, M. (2003). The experience of waiting and life after breast cancer follow-up. *Research and Theory for Nursing Practice*, 17, 153-168.

Hagerty, B. (1999). The effects of sense of belonging, social support, conflict, and loneliness on depression. *Nursing Research*, 48(4), 215-219.

- Halstead, M.T., and Hull, M. (2001) Struggling with paradoxes: the process of spiritual development in women with cancer. *Oncology Nursing Forum*, 28, 1534-1544.
- Highfield MEF (2000). Providing spiritual care to patients with cancer. *Clin J Oncol Nurs*. 4:115-120.
- Hirshberg C, Barasch MI. (1995). Remarkable recovery. New York, NY: Riverhead Books.
- Horowitz, M. (1992) Stress response syndromes. (2ed.) New York: Jason Aronson
- Howard AF, Balneaves LG, Bottorff JL. (2007). Ethnocultural women's experience of breast cancer: a qualitative meta-study. *Cancer Nursing*, 30:E27-E35.
- Janoff-Bulman, R. (1989) Assumptive worlds and the stress of traumatic events: Applications of the schema construct. *Social Cognition*, 7(2), 113-136.
- Janoff-Bulman, R. (1992) Shattered assumptions: *Towards a new psychology of trauma*. New York: Free Press.
- Jim, H. & Jacobsen, P. (2008). Posttraumatic stress and Posttraumatic Growth in Cancer Survivorship: A review. *The Cancer Journal* 14(6), 414-419.
- Kagawa-Singer, M. (1993) Redefining health: Living with cancer. *Social Science and Medicine*, 37, 295-304.
- Kernan, W.D. & Lepore, S.J. (2009). Searching for and making meaning after breast cancer: Prevalence, patterns, and negative affect. *Social science & medicine*, 68, 1176-1182.
- Kissane, D.W., Clarke, D.M., & Street, A.F. (2001) Demoralization syndrome- a relevant psychiatric diagnosis for palliative care. *Journal of Palliative Care*, 17, 12-21.
- Koenig HG, McCullough ME, Larson DB. (2001). *Handbook of religion and health*. New York, NY: Oxford University Press.
- Kvåle, K. (2007). Do cancer patients always want to talk about difficult emotions? A qualitative study of cancer inpatients communication needs. *European Journal of Oncology Nursing*, 11, 320-327.
- La Cour, K. , Johannessen, H., & Josephsson, S. (2009). Activity and meaning making in the everyday lives of people with advanced cancer. *Palliative and Supportive care* , 7, 469-479.
- Lechner, S., Zakowski, S., Antoni, M., et al. (2003). Do sociodemographic and disease related variables influence benefit finding in cancer patients? *Psychooncology* 12, 491-499.
- Lee, V., Cohen, S.R., Edgar, L., Laizner, A.M. & Gagnon, A.J. (2004) Clarifying "meaning" in the context of cancer research: A systematic literature review. *Palliative and Supportive Care*, 2, 291-303.

Lee, V. (2008). The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning. *Support Cancer Care*, 16, 779-785.

Leung, D., & Esplen, M. J. (2010). Alleviating existential distress of cancer patients: can relational ethics guide clinicians? *European Journal of Cancer Care*, 19(1), 30-38.

Lovejoy NC, et al. Cancer-related depression: part I—neurologic alterations and cognitive-behavioral therapy. *Oncol Nurs Forum* 2000;27(4):667–78; quiz 79–80.

Lovgren, M., Hamberg, K., & Tishelman, C. (2010). Clock Time and Embodied Time Experienced by Patients With Inoperable Lung Cancer. *Cancer Nursing*, 33(1), 55-63.

Lundstrom, S., Furst, C. J., Friedrichsen, M., & Strang, P. (2009). The existential impact of starting corticosteroid treatment as symptom control in advanced metastatic cancer. *Palliative Medicine*, 23(2), 165-170.

Massie, M (2004) Prevalence of depression in patients with cancer. *Journal of National Cancer Institute Monographs* 32, 57-71.

McClain, C.S., Rosenfeld, B., and Breitbart, W. (2003) Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients, *Lancet*, 361,1603-1607.

Mishel, M. (1997). Uncertainty in illness. *Annual Review of Nursing Research*, 15, 57-80.

Mount, B.M., Boston, P.H. & Cohen, S.R. (2007). Healing connections: On moving from suffering to a sense of well-being. *Journal of Pain and Symptom Management*, 33(4), 372-388.

National Comprehensive Cancer Network, N. (2007). The NCCN guideline for distress management: A case for making distress the 6th vital sign. *Journal of the National Comprehensive Cancer Network*, S(1).

National Comprehensive Cancer Network. Distress management clinical practice guidelines. Accessed August 7, 2009 at http://www.nccn.org/professionals/physician_gls/PDF/distress.pdf.

Neimeyer, R.A. (2004). Fostering post-traumatic growth: A narrative elaboration. *Psychological Inquiry*, 15(1), 53-59.

Nelson, J. (1995). Struggling to gain meaning: Living with the uncertainty of breast cancer. *Advances in Nursing Science*, 18(3), 59-76.

Park, C.L. & Folkman, S. (1997) Meaning in the context of stress and coping. *Review of General Psychology*, 1, 115-144.

Park, C. (2010). Making sense of the meaning literature: An integrative literature review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin*, 136, 257- 301.

Priggeron, HG, M.J. Horowitz, S. C. Jacobs et al. Prolonged Grief Disorder: Psychometric Validation of Criteria Proposed for DSM-V and ICD-11. *PLoS Medicine* | www.plosmedicine.org 1 August 2009, 6:: 8 : e1000121.

Puchalski C, Romer AL. (2000). Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine* 3:129-137.

Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J, et al.(2009). Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *Journal of Palliative Medicine*. 12(10):885-904.

Reynolds D. (2006) Examining spirituality among women with breast cancer. *Holistic Nursing Practice*. 20:118-121.

Rubin, SS O. B. Nadav. R. Malkinson et al. The Two-track Model of Bereavement Questionnaire (TTBQ): Development and validation of a relational measure. *Death Studies*, 33: 305–333, 2009.

Sand, L., Olsson, M., & Strang, P. (2009). Coping Strategies in the Presence of One's Own Impending Death from Cancer. *Journal of Pain and Symptom Management*, 37(1), 13-22.

Sanson-Fisher R, et al. (2000). The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer*, 88(1):226-37.

Sears, S., Stanton, A., Danoff-Burg, S. (2003). The yellow brick road and the emerald city: benefit finding, positive reappraisal coping and posttraumatic growth in women with early stage breast cancer. *Health Psychology* 22, 487-497.

Simonelli, L.E., Fowler, J., Maxwell, G.L., & Andersen, B.L. (2008). Physical sequelae and depressive symptoms in gynecologic cancer survivors: Meaning in life as a mediator. *Annals of Behavior Medicine*, 35, 275-284.

Stark D, et al. (2002). Anxiety disorders in cancer patients: their nature, associations, and relation to quality of life. *Journal of Clinical Oncology* 20(14):3137-48.

Stroebe, M., Schut, H. (1995). The dual process model of coping with loss. Paper presented at the international workgroup on death, dying and bereavement. Oxford, UK.

Taylor, E.J. (1995) Whys and wherefores: Adult patient perspectives of the meaning of Cancer. *Seminars in Oncology Nursing*, 11, 32-40.

Taylor, E.J. (2000) Transformation of tragedy among women surviving breast cancer. *Oncology Nursing Forum*, 27, 781-788.

Taylor E.J. Spirituality and the cancer experience. In Carroll-Johnson RM, Gorman LM, Bush NJ, eds. Psychosocial nursing care along the cancer continuum. Pittsburgh, PA: Oncology Nursing Press; 2006: pp. 71-82.

Tedeschi, R. & Calhoun, L. (2004). Posttraumatic growth: conceptual foundations and empirical evidence. *Psychological Inquiry* 15, 1-18.

Thompson, S.C. & Janigian, A. (1988) Life schemes: A framework for understanding the search for meaning. *Journal of Social and Clinical Psychology*, 7, 260-280

Thompson, P. (2007). The relationship of fatigue and meaning in life in breast cancer survivors. *Oncology Nursing Forum*, 34(3), 653-660.

Vachon, M.L.S. (2004). The emotional problems of the patient in palliative medicine. In: *Oxford Textbook of Palliative Medicine*, 3rd edition (eds. D. Doyle, G. Hanks, N. Cherny, K. Calman). pp. 961–85. Oxford University Press, Oxford.

Vachon MLS. (2006). Psychological distress and coping after cancer treatment. *American Journal of Nursing State of the Science on Nursing Approaches to Managing Late and Long-Term Sequelae of Cancer and Cancer Treatment*. CP Curtiss and PJ Haylock (eds). 106:3 Supplement:26-31.

Vachon, M. (2008). Meaning, spirituality and wellness in cancer survivors. *Seminars in Oncology Nursing*, 24, 218-225.

Vachon, M. (2008a). Meaning, spirituality and wellness in cancer survivors. *Oncology Nursing* 24, 218-225.

Vachon, M., Lancee, W., & Conway, B. (1990). *The needs of persons living with cancer in Manitoba*. Toronto.

Vachon MLS, et al. (1989). *Report on the needs of persons living with cancer in Prince Edward Island*. Toronto: Canadian Cancer Society.

Vachon MLS, et al. (1991). *Final report on the needs of persons living with cancer in Quebec*. Toronto: Canadian Cancer Society.

Vodermaier, A., & Linden, W. (2008). Emotional distress screening in Canadian cancer care: A survey of utilization, tool choices and practice patterns. *Oncology Exchange*, 7(4), 37-40.

Walsh, Anne E. In: *Folding back the shadows: A perspective on women's mental health*. Romans, Sarah E. (Ed.); Dunedin, New Zealand: University of Otago Press, 1998. pp. 165-176.

Weisman, A.D., and Worden, J.W. (1976-77) The existential plight in cancer: significance of the first 100 days. *International Journal of Psychiatric Medicine*, 7, 1-15.

Weisman A.D., Worden J.W. (1977). Coping and vulnerability in Cancer Patients: A Research Report. (1977). Boston: Massachusetts General Hospital.

Wilson, K.G., Chochinov, H.M., McPherson, C.J., et al. (2007). Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychology*, 26, 314-323.

Worden, J.W. (2001). *Grief counseling and grief therapy: A handbook for the mental health practitioner.* Springer Publishing Company: New York.

Zabora, J., BrintzenhofeSzoc, K., & Curbow, B. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10, 19-28.

Reading Resources

Adler, N., & Page, A. (2008). *Cancer Care for the Whole Patient: Meeting psychosocial health needs.* Washington: National Academies Press.

Carroll-Johnson, R., Gorman, L., & Bush, N. (2006). *Psychosocial Nursing Care: along the cancer continuum* (2 ed.). Pittsburgh: Oncology Nursing Society.

Ganz, P. (2007) *Cancer Survivorship: Today and tomorrow.* Springer
 Magee, S & Scalzo, K (2006). *Picking Up the Pieces: Moving forward after surviving cancer.* Vancouver: Rainbow Books.

Mayer DK (ed). (2008). *Seminars in Oncology Nursing* Issue on Survivorship. Vol 24.

Grief:

Auz MM, Andrews ML (2002). *Handbook for those Who Grieve.* Chicago: Loyola Press.

Bonanno G.A. (2009). *The Other Side of Sadness.* New York: Basic Books.

Doka, KJ (2007), *Living with Grief—Before & After Death,* Hospice Foundation.

Edelman, H. (1994). *Motherless Daughters: The Legacy of Loss.* Reading, Ma.: Addison-Wesley Publishing Co.

Grollman, E. A. (2000). *Living With Loss. Healing With Hope.*

James JW, Friedman R. (1998). *The Grief Recovery Handbook, Revised Edition.* New York: HarperPerennial.

Klass D, Silverman PR, Nickman SL. (1996). *Continuing Bonds: New Understandings of Grief.* Washington, D.C.: Taylor & Francis.

Kubler-Ross E, Kessler D. *On Grief and Grieving: Finding The Meaning of Grief Through the Five Stages of Loss.* New York: Scribner, 2005.

Nemiah, R.A. (2000). *Lessons on Loss: A Guide to Coping*. Memphis, TN: Center for the Study of Loss and Transition.

Lewis, C.S. (1961). *A Grief Observed*. London: Faber & Faber.

Schneider, J. M. (2006) *Transforming Loss: A Discovery Process*. Integra Press, East Lansing, Michigan.

Van Praagh J. (2001). *Healing Grief: Reclaiming Life after Any Loss*. New York: New American Library.

Zisook, S and Shear K. Grief and bereavement: what psychiatrists need to know. *World Psychiatry*. 2009 June; 8(2): 67–74.

Spirituality:

Dossey L. (1996). *Prayer Is Good Medicine*. San Francisco: Harper San Francisco.

Frankl, V. (1959) *Man's search for meaning*.(4th ed.) Boston, Mass.: Beacon Press

Kason Y. (2000). *Farther Shores*. Toronto:Harper Collins.

Kearney M.(1996). *Mortally Wounded*. New York: Scribner.

Kearney M. (2000). *A Place of Healing: Working with Suffering in Living and Dying*. Oxford: Oxford University Press).

Pope R. (1991) *Illness and Healing: Images of Cancer*. Hantsport, Nova Scotia: Lancelot Press, 1991.

Rossiter-Thornton J. F. (2000). Prayer in psychotherapy. *Alternative Therapies* 6(1)128-125-7).

Schultz M.L. (1998). *Awakening Intuition*. New York: Harmony Books.

Sulmasy D.P. (1997) *The Healer's Calling*. New York: Paulist Press.

Underwood M. (1995). *Diary of a Death Professional*. Hartford, CT.: Association for Death Education and Counseling.

Vachon MLS (2000). Live and learn: Cancer as a transformational experience. *The Forum Newsletter* Association for Death Education and Counseling. 26:2:5-6.

Vachon, M. (2008). The soul's wisdom: stories of living and dying. *Current Oncology*, 15 (Suppl 2, S107), 48-52.

Vachon MLS, Huggard J. (2010). The Experience of the Nurse in End-of-Life Care in the 21st Century: Mentoring the Next Generation. In: BR Ferrell and N Coyle (eds). *Textbook of Palliative Nursing*. Oxford: Oxford University Press, 3rd edition, pp. 1131-1156.

Appendix 1 - The Meaning – Making Intervention (Lee, 2004, 2008)

The following exercise may be printed out and given to the patient to complete on their own, with the nurse or with another health care provider.

The Meaning – Making Intervention (Lee, 2004, 2008)

The search for meaning is asking questions about the personal importance of a life event, such as cancer, to give it purpose and to place it within one’s total life pattern. Finding meaning can help put your life back on the path to self-realization or becoming the best you can be. Here is one way to find meaning in what has happened to you.

A. Learn about transitions.

Transitions are moves from one life event to the next. They occur in three phases:

Phase	What is Taking Place
Phase One (An Ending)	When you recognize what you have lost through the cancer experience
Phase Two (A Neutral Zone)	When you feel disconnected from the past and present, and uncertain about the future
Phase Three (A New Beginning)	When you find a new normal and recognize new opportunities and priorities

B. Use the Lifeline exercise.

Step 1. Acknowledge the present. Draw a single line to symbolize your “Lifeline”. Draw a circle on the line to represent where you are in your life now. Since the diagnosis of cancer, think about what has changed, what has not changed, what feels out of control, what is still in your control, what have you lost, what have you gained? Tell your story to a friend, write it down in a special journal, or speak it out loud to yourself.

Birth

Death

Step 2. Contemplate the Past. Your ability to get to this point is a testament of your resilience. Think of pivotal life events (positive or negative) before your cancer diagnosis, and add them to the left of your lifeline. Think of how you coped with those events. Identify what strengths helped you live through those events. Can these strengths help you to cope with your present experience with cancer? Would you do things differently today?

Step 3. Live the present, for the future. Wisdom is being able to make important life decisions in the face of uncertainty. Think of your life goals and priorities, and add them to the right of your lifeline. Think of what would allow you to look back on a life with least regret. What is important for you to accomplish today? In the next week? The next month? The next year?