Cancer-Related Psychological Distress: A Concept Analysis

Amy Gundelach, RN, BSN, OCN®, and Barb Henry, DNP, APRN-BC

**Background:** Cancer-related psychological distress, as a concept, has limited research literature substantiation. Several studies report that patients with cancer suffer from significant psychological distress; however, the description of the concept of cancer-related psychological distress has not been clearly described. Theoretical work based on the concept is also unclear.

**Objectives:** This article is a report on the concept of cancer-related psychological distress to clarify the concept as separate from non–cancer-related psychological distress and promote the use of the term in nursing practice and research across the cancer trajectory.

**Methods:** This article used a content analysis to examine the literature. The literature review for this article used CINAHL®, PsycINFO®, and PubMed to search publications from 1999–2016.

**Findings:** Content analysis of the literature revealed that the term *psychological distress* was used often with regard to distress in patients with cancer, but the concept of *cancer-related psychological distress* was not clearly defined. Four attributes encompass the concept of cancer-related psychological distress: depression, anxiety, fear, and feeling discouraged. The primary antecedent to the concept is the cancer diagnosis. The consequences can be positive or negative.

Patients with cancer are prone to psychological distress related to the cancer diagnosis (Holland & Alici, 2010). *Psychological distress* is a general term used to describe negative feelings or emotions that affect one's level of functioning and interfere with activities of daily living (Ridner, 2004). Psychological distress can result in distorted views of the self and circumstances and is manifested by sadness, anxiety, distraction, and symptoms of mental illness (Ridner, 2004). When a person has cancer, psychological distress can affect finances, family, sexuality, spirituality, and many other aspects of life. Patients living within five years of a cancer diagnosis are shown to need more attention to changes in functioning, including psychological distress (Harding, 2012). This distress may lead to major psychiatric illness; however, more commonly, the patient experiences symptoms of depression or anxiety as a consequence of having cancer. Nurses must recognize and assess for psychological distress in patients, as well as provide appropriate interventions. Nurses who pair clinical care of patients with psychosocial interventions provide an avenue for holistic focus on each patient. The purpose of this article is to define and describe the term *cancer-related psychological distress* as a person’s negative emotional response to a cancer diagnosis.

**Methods**

A literature review of CINAHL®, PsycINFO®, and PubMed databases was conducted to search publications from 1999–2016 using the key words *psychological distress, cancer or neoplasm, stress, nursing,* and *concept analysis*. The search was then refined using the following filters: publications from 2011–2016, participants aged 18 years or older, and publications written in the English language. Twenty-four articles were reviewed for potential use in the concept
analysis. Although many articles referred to it, psychological distress is poorly defined in the literature because only two articles were found that discussed the concept specifically. No concept analysis articles were found about cancer-related psychological distress.

**Concept Analysis and Theoretical Definition**

A concept analysis is a method used to identify and explore a concept and its implications for nursing practice. The Walker and Avant (2010) concept analysis method was used to examine the characteristics of cancer-related psychological distress. This concept analysis may provide nurses with a clearer image and promote recognition of cancer-related psychological distress in patients with a cancer diagnosis.

Few studies have examined the concept of distress or stress in patients with cancer. Several studies report that patients with cancer suffer from significant psychological distress (Albrecht & Rosenzweig, 2012; Mitchell, Vahabzadeh, & Magruder, 2011; Ryan et al., 2005), but the description of the concept of cancer-related psychological distress remains unclear. A certain amount of distress is normal when someone has cancer (Holland & Alici, 2010). The distress level at diagnosis reflects changed life circumstances and is a predictor of the level of distress a person will experience over time (Chambers et al., 2012).

Cancer-related psychological distress is prevalent in about 50% of patients with a cancer diagnosis and highest in patients with advanced disease and poor prognosis (Holland & Alici, 2010). Healthcare providers must identify patients with potential significant distress because 35% of newly diagnosed patients with cancer will exhibit symptoms of severe distress, such as anxiety, depression, and fear of death at some point during their illness (Chambers et al., 2012).

**Concept Use**

Cancer-related psychological distress, as a concept, has limited research literature substantiation. Psychological distress is commonly defined in medical literature as a state of emotional suffering, characterized by symptoms of depression and anxiety (Drapeau, Marchand, & Beaulieu-Prevost, 2012). Similarly, in social work, psychological distress is defined as a nonspecific negative state that includes feelings associated with depression and anxiety (Zhao, Li, Li, & Balluz, 2013).

Nursing literature often uses the National Comprehensive Cancer Network (NCCN) definition of cancer-related psychological distress to connect the concept of psychological distress to the experience of having cancer. The NCCN (2016) defines cancer-related psychological distress as an “unpleasant emotional experience of a psychological (cognitive, behavioral, and emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment” (p. DIS-2). In 2013, a collaboration between the American Psychosocial Oncology Society, the Association of Oncology Social Work, and the Oncology Nursing Society (Pirl et al., 2013) resulted in a joint position statement on distress in patients with cancer that articulates the system components and procedures necessary for addressing unmet psychological needs.

**Defining Attributes**

Four attributes are described in the literature that encompass the concept of cancer-related psychological distress: depression, anxiety, fear, and feeling discouraged. The attributes provide clarity to the concept. Depression can be difficult to detect because symptoms of depression, such as lack of appetite and fatigue, mimic the symptoms of cancer itself or the common effects of its treatment (Holland & Alici, 2010). Depression is a common attribute of a cancer diagnosis (Holland & Alici, 2010). Symptoms of depression can be influenced by a history of depression, other chronic medical illnesses, pain levels, and lack of social support (Holland & Alici, 2010). Anxiety is described in the literature as a leading psychological concern of a cancer diagnosis (Holland & Alici, 2010), and the dictionary defines anxiety (n.d.) as “a painful or apprehensive uneasiness of mind usually over an impending or anticipated ill.” Fear is related to a feeling of vulnerability. Patients fear disease recurrence, loss of projected future, and a change in support from personal relationships (Hoffman, McCarthy, Recklitis, & Ng, 2009). The dictionary defines the word discouragement (n.d.) as “a loss of confidence or enthusiasm.”

**Model Case**

A model case describes a situation in which all attributes of the concept are present. This case describes a 53-year-old woman newly diagnosed with ovarian cancer. She attended the new patient chemotherapy class with her husband. As the nurse gave the patient and her husband the education about treatment side effects and issues to report to staff, she noticed that the patient was looking out the window while acknowledging receipt of the information. The nurse asked the patient, “Is there anything I am saying that I need to review again?” The patient replied “no” in a quiet voice. The nurse asked if the patient was OK. The patient responded, I cannot sleep at night [anxiety]. I am constantly thinking the chemotherapy will make me so sick [fear]. I do not feel like eating, and I cry constantly [depression]. I cannot even think about planning for the holidays, let alone going to work. My family wants to help, but nothing can help me now [feeling discouraged].

The nurse noticed immediately that the patient was exhibiting the four attributes of cancer-related psychological distress and supported the patient by providing education and resources, as well as listening to the patient’s concerns. The nurse asked her to complete the NCCN Distress Thermometer, and the patient scored a 10 on the 0–10 scale. The nurse adjusted the plan of care by including weekly calls to check on the patient and provided her with information about a local support group.

Each of the four attributes of cancer-related psychological distress (feeling discouraged, depression, anxiety, and fear) are exemplified in this model case. The patient lost interest
in daily life and short-term planning for holiday celebrations, was unable to sleep at night, cried constantly, and was pushing her family away from supporting her. The patient stated that her life was over.

**Contrary Case**

A contrary case does not contain any of the attributes of the concept. A patient came into the clinic for laboratory tests in preparation for a chemotherapy infusion the next day. The nurse talked with the patient about how she had been doing at home while preparing to access the patient's port. The patient stated she was doing well and did not have any signs or symptoms of distress. When the nurse accessed the port, the patient was comfortable, and the procedure was completed without incident. In this contrary case, the patient was able to voice her feelings of comfort to the nurse. The four attributes of cancer-related psychological distress were explored and assessed during the appointment. The patient did not have depression, anxiety, fear, or feelings of being discouraged and left the unit feeling positive about the visit with her needs met.

**Borderline Case**

A borderline case has some, but not all, of the attributes of the concept. The nurse discussed a follow-up plan with a patient at the end of her chemotherapy regimen and asked her what her distress level had been in the past week on a scale of 0–10. The patient responded that her distress level was a 4, which still necessitates referral. She said to the nurse, I am relieved that chemotherapy was not as hard as I thought it would be. I feel as good as can be expected,

and I am glad we worked everything out with my boss by turning in the Family and Medical Leave Act paperwork. I am scared about the cancer coming back, though. What do I do now?

The nurse saw the patient was not as depressed or discouraged but noted that she continued to be fearful and anxious about the future. The nurse gave the patient a local cancer support community calendar and suggested she attend any of the classes or support groups that might interest her and fit her schedule. The nurse also gave the patient a list of providers from the insurance company, so the patient could discuss her schedule. The nurse also gave the patient a list of providers from the insurance company, so the patient could discuss her schedule. The nurse also gave the patient a list of providers from the insurance company, so the patient could discuss her schedule. The nurse also gave the patient a list of providers from the insurance company, so the patient could discuss her schedule. The nurse also gave the patient a list of providers from the insurance company, so the patient could discuss her schedule. The nurse also gave the patient a list of providers from the insurance company, so the patient could discuss her schedule. The nurse also gave the patient a list of providers from the insurance company, so the patient could discuss her schedule. The nurse also gave the patient a list of providers from the insurance company, so the patient could discuss her schedule. The nurse also gave the patient a list of providers from the insurance company, so the patient could discuss her schedule.

The patient displayed two of the four attributes of cancer-related distress. Anxiety is when a patient feels uneasiness, and fear is exemplified as being vulnerable. The patient stated she was anxious and fearful about the cancer returning; however, at the moment, she was relieved about her recovery process. A negative psychological distress outcome of a cancer diagnosis may be a mild to severe psychiatric diagnosis, such as depression, an anxiety disorder, or, in more extreme cases, suicidal ideation (Drapeau et al., 2012).

**Temporal Variables**

An antecedent is an event or situation that creates or comes before the concept (Walker & Avant, 2010). The primary antecedent of cancer-related distress is the capacity to feel and experience emotions (Massé, 2000). A second potential antecedent is a symptom described by the patient, such as pain, fatigue, or weight loss, that preceded the cancer diagnosis and has resulted in distress (Ridner, 2004). A third antecedent could be when a patient perceives a potential threat with regard to safety (Massé, 2000). A perceived threat must exist to experience distress (Bay & Algase, 1999).

Consequences are what happens after an instance of the concept, which can be negatively or positively related to the concept (Walker & Avant, 2010). A positive consequence is the patient reframing his or her life and gaining personal growth from having been diagnosed with cancer (Massé, 2000). The patient in the model case attended support groups on a regular basis. She was able to make new friends who understood her feelings. As a result, she volunteered to present her story in a news article discussing the importance of support networks in her recovery process. A negative psychological distress outcome of a cancer diagnosis may be a mild to severe psychiatric diagnosis, such as depression, an anxiety disorder, or, in more extreme cases, suicidal ideation (Drapeau et al., 2012).

**Implications for Nursing Practice**

Empirical referents relate to objective information that can be tested, repeated, and verified. Psychological distress is measured by using a validated questionnaire. The literature shows that as many as 33 tools to measure psychological distress exist (Vodermaier, Linden, & Siu, 2009). The tools are separated into three categories: ultra-short, short, and long, depending on the number of items or questions in the tool. However, the research on the validity of the tools as they relate to cancer is limited.

A study by Merport, Bober, Grose, and Recklitis (2012) compared two commonly used tools, the NCCN Distress Thermometer and the Brief Symptom Inventory (BSI) 18. The NCCN Distress Thermometer is an ultra-short, one-item self-reporting tool with a checklist of problems that can be evaluated and scored by health professionals. It asks patients about their level of distress in the past seven days. Merport et al. (2012) described the NCCN Distress Thermometer as having low reliability but moderate generalizability. The tool can be used as for quick screening to avoid unnecessary or costly referrals in newly diagnosed patients. NCCN (2016) guidelines recommend further assessment or referral to supportive services for scores of 4 or higher on the Distress Thermometer.

The BSI 18 tool, in contrast, has 18 items with three subscales (somatization, depression, and anxiety) and is considered a short tool. It is used as an initial assessment to detect psychological distress in patients with cancer and can be used to assess long-term survivors. Merport et al. (2012) reported that the BSI 18 has high generalizability, moderate reliability, and high validity, providing for identification of distress and sound clinical judgment, particularly for long-term cancer survivors. To maximize sensitivity of the tool, clinical programs need to choose the best tool for the specific patient population.
worker or psychiatric professional. Despite well-documented consequences of psychological distress, this literature review found limited nursing research seeking to explore the assessment of the defining attributes of psychological distress among patients diagnosed with cancer. Clinical nurses are at the core of assessing distress in patients and, along with the care team, determine appropriate interventions and referrals.

Fulcher and Gosselin-Acomb (2007) conducted a feasibility pilot study, using the NCCN Distress Thermometer, to institute nursing practice changes at an outpatient cancer center and to improve patient satisfaction scores. They reported that, before the study, oncology nurses did not use a standardized method for assessing cancer-related psychological distress because of perceived barriers, such as time constraints, limited knowledge of cancer-related psychological distress, and lack of awareness for potential interventions. The authors suggested using a patient empowerment model by having a booklet available for nurses to connect items on the NCCN Distress Thermometer and Problem List to specific educational materials, support groups, and referral sources (Fulcher & Gosselin-Acomb, 2007). The pilot study concluded that the NCCN Distress Thermometer was useful in the outpatient clinic in assessing cancer-related psychological distress, and nurses were able to implement interventions when a resource was available to them to provide information to the patient. Ongoing education of nurses was also critical to maintaining the use of the tool in practice.

Conclusion

Continued research is the key to increasing the value and confidence that clinicians have in using tools to measure cancer-related psychological distress. Clinicians can then translate that confidence into a greater awareness of undetected psychological distress in patients with cancer, so that appropriate actions can be taken. Another recommendation for future clinical research would be to repeat the feasibility pilot study by Fulcher and Gosselin-Acomb (2007) but with a larger nursing population and patient sample to increase validity and reliability of results. This would help nurses appreciate the valuable information gained by using the tool consistently in their practice.

References


