Theoretical Frameworks and Philosophies of Care

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Introduction

The ability to care for patients, families, and communities is predicated on the theories and evidence-based research that provide a framework for practice (Melcis, 2007). The underlying theories that drive nursing practice are an essential part of excellence in patient care. Particularly, oncology nursing is driven by theories and conceptual models that target the many components of this multifaceted and complex practice. Philosophies of care underscore the theoretical frameworks driving oncology nursing practice. This chapter will detail the role of the oncology nurse from the perspective of theory-driven—or in some cases, concept-driven—practice. The full scope of the patient and family caregiver experience, from diagnosis through long-term follow-up or end of life, will also be discussed.

Concepts, Models, Theories, Frameworks, and Patient Factors

Overview

The concepts, models, and theories that drive nursing practice are as numerous as the complexities of oncology nursing practice itself. It is important to make clear distinctions between concepts, models, and theories, as it can be difficult, for example, to differentiate an overarching theory from a concept utilized in practice.

Concepts are the building blocks from which theories are constructed; definitions of concepts differ based on the framework of their associated theories. More specifically, a concept is a body of knowledge underlying a competence based on skill acquired through experience (Machery & Lederer, 2012), or it can be thought of as an abstract idea from generalized knowledge (Hoskins, 1998). A concept or conceptual statement may have different meanings depending upon
the lens through which an individual perceives or interprets it. In this sense, an individual’s interoception, or sense of the physiologic condition of the body, may shape his or her perspective of the world (Ceunen, Vlaeyen, & Van Diest, 2016). The relationships between or among concepts define, generate, and develop the theory.

Theory can be thought of as a view of a phenomenon comprising concepts that explain the phenomenon (Fawcett, 2002). Theory can also be described as an abstract generalization that presents a systematic explanation about the relationships among phenomena under observation (Polit & Beck, 2010). Pertaining to research, Hoskins (1998) emphasized the importance of conducting every stage of a research study through a theoretical framework to capture the variables and their associations within and between one another to best explain the phenomenon under study. Haylock (2010) further noted that theory helps develop understanding of human response to illness.

Theory contains the interrelationships between established facts and emerging research evidence. It is also based on what is assumed true from prior work disseminated through scientific and theoretical publications. Theory explains, predicts, and gives direction to research through a priori predictions of the variables needed for analyses. It also assists in the selection of the most appropriate variables to guide study design. This provides a framework to compare and integrate the findings in relation to other research. Theory also drives the formation of hypotheses and subsequent interpretation of the findings. Finally, theory provides a framework for linking variables: they must have empirical or theoretical support for coexistence and testing. Logic is applied to define the relationship between variables. For example, if A is related to B, and B is related to C, then it may be assumed that A is likely related to C (Hoskins, 1998).

The operational definition within a theory describes how the concepts are measured or linked to specific aspects of theoretical frameworks and suggests how hypotheses can be tested. Theories are then useful for deriving meaning from scientific findings and developing operational definitions. Examples of theories related to the experience of cancer include Mishel’s model of uncertainty in illness, the diffusion of innovations theoretical model, stress and coping, cognitive behavioral theory, Leininger’s theory of transcultural nursing, modeling and role-modeling (MRM) theory, Roy’s adaptation model, and theories related to reasoned action and planned behavior. In essence, theories provide direction to the development and refinement of research, education, and practice.

A model, on the other hand, provides a systematic illustration of some phenomenon through a visual of related concepts that describe a specific theory. Hypotheses can continue to be developed to test and refine the theory. Thus, a model can be viewed as an illustration that adds clarity to the symbolic representation of a theory or conceptual framework. Because theories can be complex, a visual representation can demonstrate abstract concepts and clarify meaning. It is important to note that the term model is sometimes used in reference to a theory or framework in the absence of a visual depiction.

Evidence-based nursing practice can only be advanced by nurses—novices and experts alike—who understand established theories and are able to interpret phenomena and research findings by applying superior critical-thinking skills. This translation of research to practice is essential for optimizing patient outcomes.
Chapter 1. Theoretical Frameworks and Philosophies of Care

Complex Systems Theory

Complex systems theory addresses the hierarchical structure and components within a system (Clancy, Effken, & Pesut, 2008). Pertaining to health care, complex systems theory can be applied to the multidimensional milieu patients become embedded in as they proceed through their care trajectory. This is particularly salient for patients undergoing treatment for cancer. Because of the dynamic quality of patients coupled with advances in science leading to changes in evidence-based practice, complex adaptive systems can best address the physiologic and psychosocial changes a patient may experience, as well as changes at the systems level in which patient care takes place (Clancy et al., 2008).

Healthcare providers can apply complex systems theory, or more targeted complex adaptive systems, in the context of care coordination. In addressing the Institute of Medicine’s (now the Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine) focus on improving efficiency and effectiveness in healthcare systems, the Agency for Healthcare Research and Quality defined care coordination as the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care. (McDonald et al., 2007, p. 5)

An essential part of oncology, care coordination spans from screening to outcomes and includes multiple, sometimes overlapping, care practices (Taplin & Rodgers, 2010). Individual transitions across the cancer care continuum have been identified as risk assessment, primary prevention, detection, diagnosis, cancer or precursor treatment, survivorship, and end-of-life care (Taplin & Rodgers, 2010). Assessing effectiveness and shortcomings of care coordination structures and evaluating protocols for improving systems can be challenging (Schultz, Pineda, Lonhart, Davies, & McDonald, 2013).

Complex systems also bridge the communication between patient care and the recording of patient data. As patients negotiate their way through the healthcare system, their data are collected and stored, whether they are enrolled in research studies, part of institutional quality improvement initiatives, or simply having their medical records established and maintained in a large computerized system, referred to as an electronic medical record or electronic health record. With the goal of evaluating enormous amounts of pooled, de-identified patient data, clinical problems can be identified and solutions implemented at exponentially faster rates than traditional prospective, paper-and-pencil methods. The data collection process and sharing in real time using advanced technology can also be challenging (Clancy & Reed, 2016). For more information on healthcare information technology, see Chapter 22.

Understanding and using complex systems theory can guide the development of best practices in oncology care coordination and transitions while also adapting to the data science drive for improving practice and patient outcomes. Two large-scale initiatives—the Precision Medicine Initiative and the National Cancer Moonshot Initiative—are working to advance these ideas by accelerating cutting-edge research and translating effective research findings to patient care (Ashley, 2015; Neugut &
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Gross, 2016). The Cancer Moonshot is exclusively focused on components of cancer research and patient outcomes. The employment of complex systems theory in these cases is fitting because of the multiple and intricately woven components of these initiatives.

**Oncology Care Model**

The Oncology Care Model is a pilot program established by the Centers for Medicare and Medicaid Services (CMS, 2018) that applies the principles of bundled payments to cancer care with the aim of lowering costs through enhanced care coordination while improving quality. Payments are essentially bundled to cover the multiple services a patient receives, instead of being billed separately for each service. The many facets of care a patient with cancer goes through are labeled as an “episode,” and payments to providers per episode are linked with provider accountability (CMS, 2018). More specifically, care is segmented into six-month episodes initiated by outpatient chemotherapy or hormone therapy for Medicare Private Fee-for-Service patients with a diagnosis of cancer. Physician practices are responsible for the total cost of care for the six-month episodes. Being selected for this program provides an opportunity to receive monthly enhanced care coordination payments. As the pilot works to accurately track and support participating patients, it will help to inform value-based care initiatives. The Hospital Value-Based Purchasing Program (VBP) is another Medicare program designed to improve healthcare quality by paying hospitals for inpatient acute care services based on the quality of care, not only the quantity of services provided. Quality is defined as the right care at the right time in the right setting by the right healthcare professional at the right cost. Patient care experience comprises 30% of the total VBP score, of which pain is a major indicator. This is especially relevant to cancer care. Satisfaction also correlates to pain management and other patient care dimensions. With bundled payments, readmission to the discharging organization or another organization will be included in the bundled payment (Blumenthal & Jena, 2013).

**Biobehavioral Determinants and Systems Biology**

In oncology, biobehavioral determinants and systems biology are valuable frameworks for understanding the physiologic mechanisms contributing to cancer formation, progression, and outcomes. Specific to cancer formation, or carcinogenesis, evaluation of biologic systems can lead to targeted interventions for optimal outcomes. For example, investigating the regulatory mechanisms of pluripotent stem cells that can differentiate into malignant cells can enhance understanding of the cancer formation process (Davydyan, 2015). Understanding such pathways can lead to interventions to interfere with the process and ultimately prevent cancer development.

Overall, systems biology incorporates numerous scientific disciplines with an overarching focus of the fundamental genetic, epigenetic, proteomic, metabolomic, physiologic, and biologic processes that drive human function (Founds, 2009; Khalil & Hill, 2005). A unique and salient aspect of the systems biology theory is its holistic focus (Founds, 2009). Four major holistic focal points are incorporated into patient care: prediction, prevention, personalization, and participation (Schallom, Thimmesch, & Pierce, 2011). The predictive area evaluates the underly-
ing genetic or epigenetic and biophysiological functioning of the disease process and influences from behavioral and environmental factors. Prevention incorporates current health conditions and genetic predisposition into long-term planning. Personalization then takes all these factors into account in creating an individualized health plan. Finally, participation denotes the patient’s active involvement in the process (Schallom et al., 2011).

Healthcare providers cannot successfully create an individualized health plan without a complete understanding of the disease process. Because of the nonlinear nature of malignancies, systems biology incorporates mathematical and computational models to best understand cancer formation to optimize treatments that can arrest the process (Wang, 2010). These methods help capture and quantify the vast amount of information in large biologic data sets created through oncology research studies. More importantly, these computational methods help determine which treatments will be most effective for each individual because numerous variables can alter a patient’s response to treatment (Wang, 2010). In effect, systems biology helps expedite the translation of research from in vitro stages (in the laboratory) to in vivo (in the living patient) and predict optimal treatment choices based on individual factors (Khalil & Hill, 2005; Wang, 2010).

Understanding disease processes and co-occurring conditions holistically is a shifting approach in nursing academia. Systems biology is a prime example that can link associations between the environment and lifestyle factors with their impact on immune function (e.g., chronic inflammation) and subsequent outcomes of cancer, cardiovascular disease, diabetes, and respiratory diseases, among others. This global-to-cellular view can guide nursing students in the care they will provide to their patients, loved ones, and community.

In effect, nurses provide care within the realms of prediction, prevention, personalization, and participation (Schallom et al., 2011). For example, patients undergoing therapies for cancer can experience numerous symptoms. Prediction would include an understanding of the underlying contributors and mechanisms associated with the symptoms. Although complete prevention may be impossible, early interventions to mitigate symptoms may greatly enhance patient quality of life during and following cancer therapies. Personalization would incorporate specific factors such as age, health history, and behavioral factors that could influence symptom experiences. Personalization would also involve creating strategic short- and long-term plans for symptom management. Similarly, focusing on areas such as best nutritional approaches, medication adherence, and psychosocial needs can promote better outcomes while the patient is under the direct care of the healthcare team. Participation would include patient education to help promote continuation of these behaviors in the home. From this perspective, systems biology blends into the biobehavioral model.

Aside from overt behaviors that increase the risk for cancer, stress and adaptation to stress can also contribute to abnormal cell formation and progression to cancer (Godbout & Glaser, 2006). Some studies suggest that psychological stress can be a direct underlying factor leading to the onset of a malignancy, progression, or recurrence (Cohen, Janicki-Deverts, & Miller, 2007). Additionally, how patients perceive their personal influence on their cancer diagnosis can affect how they respond throughout and after treatment (Bergner, 2011).

More so, even when patients perceive that their behaviors contributed to their diagnoses, altering their behaviors can still be challenging. Smoking has a direct
causal link between a behavior and cancer development (Koul & Arora, 2010), and cessation is a prime example of how difficult it is to change behavior. Despite the overwhelming evidence, approximately 15.5% of U.S. adults smoke (Centers for Disease Control and Prevention [CDC], 2018). Many smokers who develop lung cancer report a sense of guilt or regret over their diagnosis, and both smokers and nonsmokers with lung cancer face social stigmatism—sometimes directly from their healthcare providers (Raleigh, 2010). How these feelings translate to health outcomes is less clear and warrants further study. Knowledge of the groups most likely to smoke is essential when planning primary and secondary prevention strategies and smoking cessation programs. Approximately 16.5% of African Americans smoke (CDC, 2018)—a population that suffers tremendously from smoking-related health problems (Webb, de Ybarra, Baker, Reis, & Carey, 2010). Although the non-Hispanic American Indian and Alaska Native population has the highest rate of smokers at 31.8% (CDC, 2018), studies indicate that nicotine dependency and difficulty with cessation is greater among male and female African American smokers compared to other ethnic groups (Webb et al., 2010). Further, Webb et al. (2010) found cognitive behavioral therapy to be a promising intervention for helping African American smokers to quit. A recent study showed that cognitive behavioral therapy was effective in reducing distress, specifically perceived stress and depression, among African American smokers and that reduced distress was associated with greater success in smoking abstinence (Webb Hooper & Kolar, 2015).

The biobehavioral model is also often used for cancer symptom management. For example, Budin, Cartwright-Alcarese, and Hoskins (2008) used a theoretical framework based upon the biobehavioral model, including stress and coping, to guide the development of the interventions and selection of outcome measures in their randomized clinical trial of phase-specific, evidence-based psychoeducation via video and telephone counseling interventions to enhance emotional, physical, and social adjustment in patients with breast cancer and their partners. Physical adjustment included symptom experience. Patients who received a combination of psychoeducation via video combined with telephone counseling showed a decrease in symptom severity and distress over time compared to those in the standard care disease management group.

Another example of a nurse-directed biobehavioral intervention involves exercise for cancer-related fatigue (Al-Majid & Gray, 2009). In developing this theory, researchers examined studies in the literature that investigated exercise for fatigue management among patients undergoing cancer treatment. Notably, investigations focused on underlying physiologic mechanisms for fatigue were absent. To address the gap in mechanisms, researchers developed a theoretical model to include all areas of biologic, psychobehavioral, and functional components to understand the full scope of cancer-related fatigue that would inform optimal symptom management (Al-Majid & Gray, 2009).

These studies exemplify how biobehavioral determinants and systems biology are underpinning theories that direct much of holistic nursing care throughout the cancer experience.

Clinical Reasoning and Clinical Decision Making

A vital component of excellence in nursing is the skill of critical thinking. Particularly in oncology, the nurse’s abilities to effectively evaluate a patient’s status,
assimilate information, and make autonomous decisions are essential to patient care. The conceptual models of clinical reasoning and clinical decision making can aid in this process. Clinical reasoning incorporates knowledge, experience, judgment, and various levels of cognitive processes in delivering care to patients (Simmons, 2010). For example, a patient receiving immunotherapy, specifically an immune checkpoint inhibitor, can encounter immune-related adverse events that can involve any number of organs (Germenis & Karanikas, 2007; Kottschade et al., 2016). Monitoring patients for the onset of these side effects and taking immediate action can reduce the risk of serious and long-term complications, aiding in a successful outcome. With an understanding of the mechanisms and potential outcomes, the nurse can use the clinical reasoning process to guide decisions.

Dovetailing clinical reasoning is clinical decision making. Decision making begins with a problem that needs a resolution coupled with a degree of uncertainty as to how to resolve the problem (Muir, 2004). If knowledge and experience are key elements in decision making, then where does this leave the novice nurse, who may have recent textbook knowledge yet little clinical experience? Because the novice nurse lacks experience, likelihood error is higher (Saintsing, Gibson, & Pennington, 2011). Some suggestions for decreasing errors and increasing accurate decision making involve enhancing critical-thinking skills in nursing school curricula, coupled with providing technology-based tools in the clinical setting for easy access to information that the nurse might not have yet committed to memory (Saintsing et al., 2011). To enhance this process, many nursing education programs have adapted a concept-based curriculum. This approach shifts the focus of curricula from one that is disease centered to a knowledge base that is applicable across multiple diseases, settings, and circumstances (Duncan & Schulz, 2015). The emphasis on conceptual learning fosters deeper levels of critical thinking (Giddens, Wright, & Gray, 2012). Additionally, in clinical practice, peer mentoring programs and working and consulting with more experienced nurses when a solution is unclear are paramount for optimal and safe patient care. Over time, increased knowledge and experience promote effective decision-making processes.

Standards that represent the evidence-based supportive literature, as well as accountabilities of each member of the interprofessional healthcare team, provide a framework to generate policies and procedures, protocols, guidelines, and care pathways. National guidelines and patient care documents also promote evidence-based options in decision making that reflect the most current standard of care. These documents are developed by panels of experts in the field of oncology (American Society of Clinical Oncology, 2016; National Comprehensive Cancer Network®, n.d.; Oncology Nursing Society, n.d.).

It is also vital for patients to participate in the informed decision-making process. Evidence-based practice guidelines can assist the healthcare provider in offering treatment options. These guidelines also consider quality of life and supportive care so that patients have information to make informed decisions (Peppercorn et al., 2011). Many factors influence patients’ healthcare decisions, and the theories of reasoned action and planned behavior have an underlying role in decision making. These theories take into consideration that individuals are rational, make use of information before making a decision, and evaluate the implications of their decisions prior to acting (Gullate, 2006). Understanding these driving forces can direct the nurse in helping and supporting patients through their decision-making processes.
Although most institutions providing cancer treatment boast excellence in their patient care, care transitions from one phase of treatment to another sometimes leave patients feeling lost and vulnerable. One study identified six barriers to cancer care coordination (Walsh et al., 2010):

- Recognition of roles and responsibilities of healthcare providers
- Ability to implement comprehensive interprofessional team meetings
- Problems with care transitions
- Communication challenges between primary care providers and specialists
- Access to health services
- Limited resources

One way to deal with these barriers is through the patient navigation model, a psychosocial approach to ensuring that patient needs are met through every phase of the diagnosis, treatment, and recovery. The components of patient navigation include providing support, assistance with finding resources, assistance with practical issues, and community support systems (Pedersen & Hack, 2011). Patient navigation programs often involve members of the healthcare team designated as patient navigators to guide patients through the healthcare system. A recent systematic review of 13 patient navigation studies that targeted patients with breast cancer during treatment and survivorship found that a patient navigation model is most effective for post-treatment surveillance (Baik, Gallo, & Wells, 2016). Aside from this review, patient navigation has been found to be effective throughout various cancer care time points and on multiple levels, including targeting disparities in healthcare screening. For example, African Americans have higher incidence and mortality rates of colorectal cancer compared to other racial groups, in part from lack of recommended screening (R. Williams et al., 2016). One recommendation to improve this disparity is through a patient navigation model (R. Williams et al., 2016). The patient navigation model has been used in many facets of oncology care, including community-based efforts to increase cancer screenings among populations who have limited access to care. The Avon Foundation, for example, instituted the Education and Outreach Initiative Community Patient Navigation Program to increase mammography screening among African American women in the United States (Mason et al., 2011). In this program, community-based patient navigators hosted recruitment events, referred participants to nurse practitioners who aided with eligibility for low-cost or free mammograms, and conducted follow-up telephone calls to encourage adherence to mammography appointments (Mason et al., 2011).

A navigation care delivery model can support patients as they navigate complex combined therapy, including surgery, radiation oncology, and medical oncology modalities, while grappling with individual barriers to care. A navigator can help patients access timely clinical and supportive resources throughout the care continuum of primary therapy, recovery, survivorship, and end of life. The navigation model considers the physical, psychological, social, financial, and spiritual aspects of care and provides a framework for continued informed decision making. Early navigation models have demonstrated the ability to mitigate delays in resolution after positive screening (Bensink et al., 2014; Carle et al., 2014). They can also facilitate informed decision making when a patient and family are faced with multiple complex options at a difficult time in diagnosis and treatment (Esparza, 2013) and when quality health and psychosocial care is not
easily accessible throughout all phases of the cancer continuum (Oncology Nursing Society, 2017).

Similarly, patient navigation programs have helped U.S. Hispanic populations improve both mammography and colonoscopy screening rates, in addition to facilitating timely treatment in the event of a cancer diagnosis (Robie, Alexandru, & Bota, 2011). Patient navigators can not only provide access to timely care and disseminate information, but they can also help minimize anxiety and feelings of helplessness throughout the process.

**Caring**

Caring is inherent to nursing and has often been perceived as the essence of nursing (Bassett, 2002). Particularly in oncology, nurses not only provide physical care but also are empathetic to the patient experience. Caring as a theoretical concept was described in the early 1980s using a substruction method. *Substruction* is a strategy used to critique a theory and methodology through analyzing the theory’s components and their hypothesized relationships (Dulock & Holzemer, 1991). Caring as a theory was substructured with analysis of components comprising awareness of a need, knowledge to address the need, assessment of the relationship between the need and intended action, and evaluation of a positive change as an outcome of the action (Gaut, 1983). Although such analysis of caring is regimented, the perception and actualization of implementing care can vary among individuals. Some may view good caring as expert delivery of evidence-based practice, whereas others may define good caring as provided by those who show humanistic qualities (Bassett, 2002). Bassett (2002) described four categories of caring as nurses’ feelings, nurses’ knowledge and competence, nurses’ actions, and patient and family outcomes and nurses’ rewards (satisfaction from patient care). These areas encompass all aspects of what can be viewed as the caring continuum from the knowledge base and physical delivery of care to the emotional support. Optimal caring includes patients feeling a level of trust in the nurse. Conceptually, trust in patient care is not clearly delineated, but in general terms, it relates to the amount of confidence a patient has in the nursing care (Dinç & Gastmans, 2012).

Perceptions in nursing care play an integral role in patient well-being. For example, a study focused on perceptions of caring among patients with cancer in Beijing, China, noted similar themes, including professional knowledge, care delivery, and emotional support (Liu, Mok, & Wong, 2006). Additionally, a multicentered international assessment found that trust in nurses was integral and included the components of perceived nursing care quality, individualized care, and health status (Charalambous et al., 2016). As caring from all vantage points is within the heart of nursing, it forms the foundation to all phases of the patient and family/caregiver experience from diagnosis through the outcome of survivorship or end of life.

**Patient–Provider Relationships and Communication**

Establishing a good rapport between the patient and healthcare team is essential for optimizing care for patients with cancer. In the initial stages, good communication is vital for obtaining a thorough patient history and report of the presenting issue. When the patient confronts a physical health problem, effec-
tive communication throughout care can become secondary to treating the ail-
ment. Healthcare education, though, is starting to emphasize the importance of
communication along with learning the essentials of the biopsiologic aspects
of human functioning. It has become clear that healthcare providers who are
unskilled at relationship building and effective communication can leave patients
feeling isolated and daunted. For the past few decades, a concerted effort to
enhance communication skills has become part of curricula in the health pro-
fessions (Beckman & Frankel, 2003). Furthermore, the physical, psychological,
social, cultural, spiritual, and financial needs that have been identified among
cancer populations might be considered in the context of MRM theory (Erick-
son, Tomlin, & Swain, 1983), holistic philosophy, and symptom clusters (Hay-
lock, 2010). MRM theory is built on the components of knowledge, resources,
and actions (Haylock, 2010). Patient–provider relationship building and commu-
ication skills are initially learned in the classroom but do not always translate
to the real-world clinical setting where time constraints and unexpected issues
needing immediate attention are common. Additionally, effective communica-
tion becomes critical when particularly sensitive news needs to be relayed to the
patient and loved ones. Barriers to effective communication have been identified
as time constraints, lack of emphasis in training, poor modeling by senior pro-
viders, disinterest in learning how to communicate, and lack of knowledge about
resources in learning such skills (Orgel, McCarter, & Jacobs, 2010). As the health-
care provider gains experience and proficiency performing the necessary clinical
activities, experienced mentors can guide and model good patient rapport (Beck-
man & Frankel, 2003).

The process of building good rapport through effective communication with
patients may be healthcare provider directed but must also allow for the patient to
match the provider in creating an optimal working relationship. A study by Berry,
Wilkie, Thomas, and Fortner (2003) unveiled unbalanced patient–provider com-
unication when discussing pain in patients with prostate or head and neck can-
cer. The providers tended to dominate the conversations, at times even interrupt-
ing the patients, inhibiting patients from fully disclosing pertinent information
or asking questions (Berry et al., 2003). Similarly, an investigation of the Health
Information National Trends Survey revealed poor patient-centered communica-
tion among cancer survivors (Blanch-Hartigan et al., 2016). Nurse-led follow-up
with patients can improve such a communication deficit. Having a nurse trained
in a specific specialty track and follow up with patients, with the patient able to
contact the nurse as needed, has proved to be particularly effective in cancer pain
management and other symptom-related issues (Salander, 2010).

Understanding the importance of the patient–provider relationship and good
communication skills is key for optimizing nursing care—something nurses have
long intuitively recognized. Nurse practitioner interactions with patients are
focused on these relationships. Using a biopsychosocial framework, having the
expertise, being affirming in dialogue, and engaging patients can lead to strong
communication and better outcomes (Bentley, Stirling, Robinson, & Minstrell,
2016).

Various communication frameworks drive practice. The patient-reported out-
comes (PRO) model, used to assess patient satisfaction and health-related out-
comes, encompasses several of these attributes and has been used in thousands
of research studies. In fact, it is a driving force in the care of patients with can-
cer. For example, an international, interprofessional working group from the International Consortium for Health Outcomes Measurements defined standards for patient-centered outcomes for patients with lung cancer (Mak et al., 2016). The PRO model places focus on the individuals involved in the communication, the relationship development process, and specific components of communication activities. These include how messages are translated from one person to another, such as feedback and feedforward mechanisms (Feldman-Stewart & Brundage, 2009). Additionally, the PRO model accounts for the multidimensionality of relationships and their environments (Feldman-Stewart & Brundage, 2009). In nursing practice, understanding and using such tools can greatly improve a patient’s experience and well-being.

**Symptom Experience**

Nursing research on cancer symptom management has made tremendous advancements as the concepts that define it become more precise and their associations to each other more refined, generating theories that better explain and describe the symptom experience phenomenon. It is such an important, nursing-centric focus that it is one of the key priority areas for the National Institute of Nursing Research (n.d.) and the Oncology Nursing Society (Knobf et al., 2014). In oncology nursing research, symptom experience comprises the number of symptoms, the severity of symptoms, and the amount of distress experienced (Armstrong, 2003; Goodell & Nail, 2005). *Symptom clusters* were identified and described as having three or more co-occurring symptoms related to one another (Dodd, Miaskowski, & Lee, 2004).

Examples in the literature are numerous. Budin et al. (2008) described the development, testing, and utility of the Breast Cancer Treatment Response Inventory, an instrument that captures the symptom experience of women with breast cancer. Consistent with the definitions of Armstrong (2003) and Goodell and Nail (2005), the inventory is a valid and reliable tool to determine and monitor the number of symptoms, the severity of those symptoms, and the amount of distress experienced by patients with breast cancer. Many other valid and reliable instruments exist that capture individual and multiple symptoms that patients with cancer experience. Developed by the National Institutes of Health, the Patient-Reported Outcomes Measurement Information System is a valid and reliable tool that can be tailored to specific patient populations (Craig et al., 2014; Eisenstein, Diener, Nahm, & Weinfurt, 2011; National Institutes of Health, n.d.).

Creating a conceptual model to best describe symptom experiences in patients with cancer, Dodd, Miaskowski, and Lee (2004) developed an initial model that was then updated by Miaskowski, Aouizerat, Dodd, and Cooper (2007) to explore how genetic determinants may be a predictor of symptom severity in different groups of patients with cancer. Brant, Beck, and Miaskowski (2010) continued to expand the conceptual model. The researchers suggested that further exploration was needed to determine whether the definition could be modified to include two or more symptoms. This is consistent with the psychology and psychiatry literature in which the concept of symptom management including symptom clusters is well developed. For example, Kim, McGuire, Tulman, and Barsevick (2005) conducted a review and critique of psychology, psychiatry, general medicine, and nursing literature regarding symptom cluster research. Their findings revealed that psychology
and psychiatry disciplines conducted studies to examine this concept and agreed that the number of symptoms in a cluster is not important, but they concluded the focus should be the major antecedent of a symptom cluster of two or more symptoms that is the predisposing initiator. Understanding and anticipating that symptoms often occur in clusters can help in reducing the symptom experience through early interventions. Importantly, being able to identify patients at risk for worse symptom experiences prior to the start of treatment can lead to best practices for mitigating symptoms during treatment.

Additionally, it is important to understand underlying mechanisms that may influence the symptom experience. Hammer, Motzer, Voss, and Berry (2010) described the challenges of glycemic control in older adult hematopoietic stem cell transplant recipients. Factors including older age, history of diabetes, nutritional instability, medications (e.g., glucocorticoids, immunosuppressants), decreased physical activity, and physiologic and psychological stress contribute to glycemic instability, which, in turn, has been found to have associations with risks for adverse outcomes, including infections and mortality (Derr, Hsiao, & Saudek, 2008; Hammer et al., 2009, 2016). These factors may also contribute to symptom experiences—physiologically through inflammatory mediators and on other levels through the synergistic effect of coping with these instabilities and outcomes concurrently with symptoms initially induced by the malignancy and related treatments (Devaraj, Venugopal, Singh, & Jialal, 2005; Hammer et al., 2015; Mantovani, Allavena, Sica, & Balkwill, 2008). This captures the four major points incorporated into patient care: prediction (risk of glycemic instability), prevention (diet, exercise, and behavior), personalization (healthcare plan), and participation (patient partners in the healthcare plan) (Schallom et al., 2011). Understanding these associations can guide the healthcare team in symptom management through early and targeted interventions. The symptom experience model can serve as a fundamental mechanism through which understanding and actions can be effectively initiated.

**Cultural Concerns**

Patient populations are often heterogeneous in nature. They enter the healthcare system coming from various backgrounds, environments, and experiences. Patients also have diverse cultural backgrounds that may vary from the predominant culture in which the healthcare facility resides. Culture also contributes to how patients receive, assimilate, and deal with health-related issues. Undergoing treatment for cancer can highlight such cultural differences. The diagnosis itself may be influenced by genetic and epigenetic determinants inherent within ethnic or racial groups—the defining gene and phenotype expression of the population that comprises the culture. Cultures can also include populations from varying ethnic or racial backgrounds. It may not be possible to be culturally competent for all cultural groups, but healthcare providers can achieve an appropriate level of awareness and respect. Cultural awareness encompasses being mindful, respectful, understanding, and, whenever possible, accommodating to the norms of the culture of the patient. This includes awareness of race, gender, traditions, beliefs, customs, and values (Schim, Doorenbos, Benkert, & Miller, 2007). Culture can also include sociopolitical identification such as sexual orientation and political party affiliation.
Delivering culturally competent nursing care is still best described through Madeline Leininger’s (2002) theory of transcultural nursing. This theory incorporates many facets of health care and culture, including but not limited to the following aspects (Leininger, 1999, 2002):

- Interrelationships of culture and care on well-being, health, illness, and death
- Comparative cultural care
- Holistic and multifaceted culturally based care meanings and practices
- Global cultural diversities
- Incorporation of multiple individual influencing factors (e.g., culture, values)

To comprehensively and effectively provide culturally sensitive care, the healthcare team must consider the dimensions of communication, space, time, social organization, environmental controls, and biologic variations (St Clair & McKenny, 1999). From these viewpoints, providing culturally sensitive nursing care begins with a basic understanding of the culture, including the norms and beliefs. Investigation through the literature, coworkers from the same culture, and the patient and family members themselves can educate the healthcare team. For example, inquiring about cultural or religious dietary needs and ensuring that those needs are met during a hospital stay may be highly important to the patient (Schim et al., 2007). It is also important, however, to not stereotype cultures and be presumptive in delivering care (Kemp, 2005). To avoid such assumptions, it is essential for nurses to first have a solid understanding of their own cultural beliefs, values, and judgments (Maier-Lorentz, 2008). The next step is to inquire about the patient's desires regarding how he or she would prefer the care be delivered that would accomplish the goals of care while maintaining cultural beliefs. Points of consideration include assessing how the patient and family members view the disease and how it has affected their lives (Mendes, 2015). This can become particularly sensitive during stages of palliative or end-of-life care. A study by Huang, Yates, and Prior (2009) evaluated nurses' perceptions and accommodations of cultural needs for patients receiving palliative care. Understanding of the individual's cultural needs came with experience, which helped to provide culturally respectful care (Huang et al., 2009). An interesting example of cultural influence on patients' perception is how patients interpret pain. From one cultural perspective, pain was a sign of life and thought of in a positive light, and from another cultural perspective, pain was a result of negative behaviors in a past life (Huang et al., 2009). Taking all such considerations into account when providing care can lead to a respectful and positive experience for the patient, family members, and the healthcare team themselves.

Resilience

The essence of resilience can have different meaning to different people. Related to health, the application of resilience lies within well-being, quality of life, and responses to health challenges (Windle, Bennett, & Noyes, 2011). Resilience encompasses a dynamic perspective of individualized coping abilities in dealing with stress and adversity (Grafton, Gillespie, & Henderson, 2010). Central to the ability to cope is an individual's sense of an innate energy or motivating life force composed of certain characteristics, including coping along with adaptability, faith, hardness, optimism, patience, self-efficacy, self-esteem, sense of humor, and tolerance (Grafton et al., 2010). Optimism, in particular, is an
integral component of successful resiliency (Southwick & Charney, 2012). Additionally, specific psychobiologic mechanisms have been identified in relation to adaptation to stress (Charney, 2004). In oncology, having the positive attributes of resiliency is extremely beneficial for patients, loved ones, and healthcare providers themselves.

Patients with cancer often display highly resilient states of being. A qualitative study evaluating resilience in patients undergoing hematopoietic stem cell transplantation revealed that hope for survival helped strengthen their courage and resilience (Coolbrandt & Grypdonck, 2010). In the study, patients benefited from writing a positive story about their experiences. This helped them to find meaning behind the suffering that accompanied the treatment. Patients further relied on the nurses and physicians to keep them encouraged; however, the overall process of taking an active role, instead of a passive one, gave them a sense of autonomy and enhanced resilience (Coolbrandt & Grypdonck, 2010). Similarly, a study investigating resilience in patients with metastatic colorectal cancer found a correlation between resilience and hope (Consentino Solano, Gomes da Silva, Agurtov Soares, Ashmawi, & Edson Vieira, 2016). These attributes have also been associated with self-esteem, positivity, and an overall sense of well-being (Consentino Solano et al., 2016).

A resilient attitude can significantly help many other oncology populations and can be beneficial in other situations related to a cancer diagnosis. Adolescents with cancer, for example, benefit greatly from psychosocial guidance for a positive outlook (Haase, 2004). This need became so recognized that the Adolescent Resilience Model (ARM) was established. ARM also accounts for the various developmental phases throughout young life. The concepts that make up ARM are classified as risk, protective, and outcome factors (Haase, 2004):

- Illness-related risk—uncertainty, disease and symptom distress
- Family protective—family atmosphere and support, resources
- Social protective—social integration, healthcare resources
- Individual risk—defensive coping
- Individual protective—courageous coping, derived meaning
- Outcome—resilience, quality of life

In application since its development, the ARM model has proved effective in enhancing resilience among adolescents and young adults with cancer. A recent study found that patients aged 12–24 years old ultimately adapted resilience per the ARM model strength factors; some were earlier adapters than others, but all increased positivity and a sense of purpose (Ishibashi et al., 2016).

Resilience is also an important mechanism for all age groups when facing cancer recurrence. When cancer recurs, patients can feel depressed or anxious, lose their sense of hope, and have an increased fear of death (Andersen, Shapiro, Farrar, Crespin, & Wells-Digregorio, 2005). An interesting example in one study found that patients with breast cancer recurrence were quite resilient and did not report higher levels of global distress or quality-of-life disruption; however, patients did report increased levels of stress focused on the cancer itself (Andersen et al., 2005). Findings in studies like these can help uncover nuances sometimes overlooked.

Culture can also influence resilience. Hispanic populations have high resilience and tend to have better health outcomes compared to non-Hispanic White populations (Gallo, Penedo, Espinosa de los Moneteros, & Arguelles, 2009). Although some U.S. Hispanic populations may be in lower socioeconomic situations that can
create barriers to certain resources such as mainstream healthcare systems, Hispanic culture embraces social resources, strong family support, and religiousness during adversities, boasting a strong impact on outcomes (Gallo et al., 2009).

Within all cultures and socioeconomic levels, resilience comes from within but can clearly be enhanced by surrounding support. Autonomy is one facet that strengthens resilience. Oncology nurses can aid in strengthening patients’ sense of autonomy and resilience through assessing patients’ initial state of being, encouraging activities such as positive story writing, and directing psychosocial services to them as needed.

**Self-Help**

As noted by Haylock (2010), individual worldviews, the current health challenge, and the self-perception of anticipated health outcome will guide a patient’s self-care actions. From this point of view, promoting self-help among patients with cancer can enhance positive health behaviors and coping strategies and motivate patients to action. For example, in a peer-guided self-help group, patients can use each other as a support system. Supported by nurses in the organization through fostering relationships among members, cancer support groups can be an invaluable tool for patients. Of particular importance, patients identified the need to relate to others who are going through the same experiences—something they could not achieve through their family members and loved ones. The effectiveness of support groups can be related to the helper therapy principle that describes the psychological and physiologic benefits that people receive from helping others (Lepore et al., 2014). Further, this benefit is seen in both in-person and online support groups (Lepore, Buzaglo, Lieberman, Golant, & Davey, 2011; Lepore et al., 2014).

Aside from the support group structure, patients can promote self-care through their daily activities. Exercise can decrease symptom burden, enhance functional capacity, and improve overall health perceptions (Hacker, 2009). Self-help exercise programs have been found to be effective among cancer populations (Jansen et al., 2016). Similarly, self-help can be effective, to some degree, for aiding in smoking cessation (Chan, Cheung, Wan, Wang, & Lam, 2018).

Self-help can also come in the form of information gathering. The seminal work by Lazarus and Folkman (1984) on stress and coping theory poses that information is a resource that enhances coping. This theory translates to the current era of readily available, real-time information through the Internet. Indeed, many patients access the Internet as a resource for finding information and help. This can be challenging for individuals in lower socioeconomic situations who may not have access to computers. To decrease socioeconomic disparities with access to health information, researchers evaluated the innovative approach of providing computers to low-income individuals newly diagnosed with breast cancer (Lu, Shaw, & Gustafson, 2011). Patients used the computers to contact healthcare providers for consulting on issues related to their diagnosis and treatments. The use of this tool enhanced self-efficacy, participation in health care, and patient–provider relationships (Lu et al., 2011). Another online tool to promote self-help for fear of cancer recurrence is currently under investigation for effectiveness using cognitive behavioral therapy (van Helmond, van der Lee, & de Vries, 2016). In this study, patients participated in online cognitive behavioral therapy modules with the goal
of reducing fear after cancer therapy (van Helmond et al., 2016). These types of self-help programs can enhance a patient’s perception of autonomy and control over an overwhelming situation. Subsequently, enhanced perceptions of autonomy and control can empower patients and improve their experiences significantly.

**Integrative Health Care**

Unique to the science of nursing is that care encompasses the physical, psychological, social, cultural, spiritual, and financial domains. Because biobehavioral and systems biology theories and models include biologic, physical, psychological, social, cultural, spiritual, and financial needs, they provide a framework to capture how these dimensions vary throughout the cancer trajectory based on personal priorities and disease concerns. For example, during the diagnostic period, survival is a major concern, whereas in ongoing recovery, quality-of-life concerns may prevail. Working with patients at all stages to meet their current needs will help with optimizing quality of life throughout the disease trajectory.

Integrative health care includes but is not limited to the use of mind–body strategies, fitness, meditation, massage/touch therapies, yoga, music, acupuncture, relaxation techniques, and homeopathy to promote well-being or treat health conditions. Results of randomized clinical trials that have examined integrative healthcare therapies collectively demonstrated these practices to be effective for physical, psychological, social, cultural, and spiritual aspects of caring (Cassileth & Gubili, 2008; Deng & Cassileth, 2014). On this concept, the Academic Consortium for Integrative Medicine and Health (n.d.) offers the following definition:

> Integrative medicine and health reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic and lifestyle approaches, healthcare professionals and disciplines to achieve optimal health and healing. (para. 6)

Nursing, with its holistic view, is well positioned to foster and support integrative health into cancer care. Guided by the tenets of key theories such as MRM theory, integrative health can provide holistic patient care for various populations (Haylock, 2010). More specifically, if certain basic needs are not met, it can lead to poor self-perceptions and, with that, a deficit in the ability to cope with stressors (Erickson et al., 1983). For patients with advanced cancer, MRM theory can be applied to needed care, encompassing all the inherent complexities and dimensions at this stage of disease (Haylock, 2010). In this scenario, helping to fulfill the needs of the patient can help reduce the level of stress.

**Survivorship**

The National Coalition for Cancer Survivorship (n.d.) regards patients with cancer as survivors from the moment of diagnosis, as they are presently living with the malignancy. Survivorship, however, is sometimes thought of within the context of post-treatment remission. Post-treatment survivorship includes a focus on disease-specific concerns (continuous follow-up evaluations to screen for cancer recurrence or new onset of malignancy), as well as long-term symptom management and life considerations (e.g., fertility issues, nutritional considerations) (Gage et al., 2011). Patients who survive five years or more are considered long-term sur-
vivors and can experience a number of physical and psychosocial issues, including continued symptoms, psychological distress, challenges with sexual intimacy, social relationship problems, financial difficulties, and an overall decreased quality of life compared to their prediagnosis life (Foster, Wright, Hill, Hopkinson, & Roffe, 2009). Various other factors can also influence the cancer survivor’s quality of life. In a study of 152 long-term survivors of breast cancer, positive and negative influences of having had cancer were identified. The study found that physical functioning directly related to the impact of cancer and worsened mental functioning had strong negative impacts (Bouskill & Kramer, 2016).

Long-term survivorship is also common among people diagnosed with cancer as children. Lund, Schmiegelow, Rechnitz, and Johansen (2011) evaluated psychosocial late effects in survivors of childhood cancer and found that patients rated their health-related quality of life equal to or better than sibling or population controls. Long-term effects among survivors of childhood cancers, however, are multilayered. Multiple long-term symptoms, risks for chronic health conditions, and premature death compared to the general population can disrupt quality of life (Hjorth et al., 2015).

Several theories can be incorporated into the survivorship stage in all age groups. With the encouragement of healthcare providers, many adult survivors of cancer will have the incentive to change some of their prior negative health behaviors. This may include better nutrition, exercise, reduction of alcohol consumption, and smoking cessation. However, altering behavior can be extremely challenging. The transtheoretical model and social cognitive theory (SCT) have been used to drive interventions for behavior change among cancer survivors (Stacey, James, Chapman, Courneya, & Lubans, 2015). The transtheoretical model focuses on precontemplation, contemplation, and action as stages of readiness for behavior change (Saunders, Frederick, Silverman, Nielsen, & Laplante-Lévesque, 2016), but SCT encompasses self-development, adaptation, and self-renewal over time as life shifts (Bandura, 2001). The context of both models can be applied to patients with cancer and their loved ones. Stages of change during and following cancer therapies, as well as adaptations to living with the history of cancer and constant possibility of recurrence post-treatment, can reshape perceptions of life. Sometimes positive outcomes include the health threat as a motivator for making behavior changes. Healthcare providers can support this through motivational interviewing as a technique using social learning and SCT to guide the process (Pinto & Floyd, 2008). In one study, researchers used SCT to guide an intervention for improved nutrition and physical activity among cancer survivors. Findings revealed that the constructs of SCT, including self-efficacy, behavioral goals, outcome expectations, impediments, and social expectations, had influences at varying time points, with participants achieving overall success in health behavior changes (Stacey, James, Chapman, & Lubans, 2016). Cognitive behavioral theory and the Roy Adaptation Model have also been used in survivorship with success. Cognitive behavioral theory assumes an interconnection among thoughts, feelings, and behaviors. Cognitive behavioral theory–based interventions can consist of components to enhance education about the behavior, establish goals, self-monitor, analyze behaviors, and enhance coping and social skills to alter underlying negative emotions that may be driving undesirable behaviors (Pinto & Floyd, 2008). The Roy Adaptation Model focuses on adapting to the altered environment through physiologic and psychological perspectives (Pinto & Floyd, 2008). Adding to this armament of theories
guiding change, the social scientist Everett Rogers’ diffusion of innovations theoretical model incorporates the domains of innovation, adoption, communication, and social relationships (Dooks, 2001; Rogers, 2004). Although this model has evolved since its inception in the early 1950s, the underlying premise of how innovation diffuses through communication channels into a social system has remained (Rogers, 2004). In the context of adapting to a lifestyle change in cancer survivorship, the innovation is in acting to live a healthier lifestyle with support. Communication and social relationships in support of this change, in this example, would come from the healthcare team, family caregivers, and people in the individual’s inner circle.

Survivorship has become so prevalent that educational programs on survivorship for healthcare providers are being established. One highly successful program offered nationwide through the City of Hope focuses on care coordination, communication, and collaboration between the patient and healthcare team members (Grant, Economou, Ferrell, & Uman, 2015). Nurses working with patients who have entered the survivorship stage can apply these theories and engage in such programs to guide patients in adapting to their post-treatment life. Because each patient’s cancer experience is unique, both physiologically and psychologically, consideration of individualized needs is essential.

The Omics Landscape

Recent advances in cancer detection and treatment in relation to genetics, genomics, and other “omics” (proteomics, metabolomics, pharmacogenomics, etc.) have provided improved outcomes and presented new challenges in the treatment of patients with cancer. The Precision Medicine Initiative and Cancer Moonshot have accelerated research and its translation to clinical practice, particularly in oncology (Ashley, 2015; Kaiser & Couzin-Frankel, 2016; Neugut & Gross, 2016). How does theory drive these research and practice endeavors in which nurses at many levels are involved in various aspects? Or could this level of science be viewed as atheoretical? Using a holistic lens, healthcare providers can apply multiple theories to ensure optimal patient care and outcomes. Multiple theories exist under the medical model for cancer (Baron & Storb, 2006; Pantziarka, 2016). For nursing, incorporating the omics sciences into educational material is essential for providing excellence in patient care. Rogers’ diffusion of innovations theory incorporates the dimensions of innovation, communication for dissemination, time, and the social system—a perfect driving theory for establishing and testing competencies in nursing education related to genomics (Calzone et al., 2012). As research, science, and care practices evolve through the application of omics sciences, the utilization of theories to optimize patient care and outcomes will certainly be delineated.

Uncertainty in Illness

Mishel’s model of uncertainty in illness describes the art of mastery over uncertainty and an adverse situation as being either a danger or an opportunity (Mishel, Padilla, Grant, & Sorenson, 1991). Mastery, in this context, refers to the belief of being able to alleviate or transcend the impact of an adverse event and uncertainty within the context of it having the quality of vagueness. It is the vagueness within uncertainty that mastery can overcome in evaluating a situation and determining
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if it is a danger or opportunity (Mishel et al., 1991). Within the context of illness, uncertainty has a psychological power that can influence outcomes (Kazer, Bailey, & Whittemore, 2010).

The uncertainty in illness model is applicable to oncology nursing practice focused on patients of all ages with various malignancies and in various phases of the cancer experience. With this model applied to children and adolescents undergoing treatment for cancer, a study identified anxiety and distress as key psychosocial stressors related to uncertainty (Stewart, Mishel, Lynn, & Terhorst, 2010).

Other researchers adapted this model as an intervention for the management of patients with breast and prostate cancers by creating a cognitive schema about the uncertainty, then using it as a tool for finding ways to take control over areas that initially appear without control (Kazer et al., 2010). Mishel et al. (2009) directly applied this tool to men with prostate cancer during their treatment decision-making process. Uncertainty areas that showed improvement in both Caucasian and African American men included knowledge about the cancer, problem-solving ability, communication (patient–provider communication and medical communication competence), informational resources, and decisional regret (Mishel et al., 2009). Similarly, a study using Mishel’s model to assess uncertainty in men with prostate cancer who were being managed through watchful waiting identified appraisal of danger and appraisal of opportunity domains as underlying themes to uncertainty (Bailey, Wallace, & Mishel, 2007).

Oncology nurses can use the uncertainty in illness model as a method of understanding the psychological distress that uncertainty brings to patients with cancer. Furthermore, they can incorporate the instrument developed by Mishel to help patients find areas of control, thus decreasing the level of distress the uncertainty causes. This model can be applied throughout all phases of the cancer experience and can aid family and caregivers as well (Stenberg, Ruland, Olsson, & Ekstedt, 2012; A.-L. Williams, 2014).

Phases of the Cancer Experience

The cancer experience includes the phases of screening, diagnosis, treatment, immediate recovery, ongoing recovery and survivorship, and end-of-life care. Treatment intention is conceptualized as cure, control, or palliation (Denlinger et al., 2017). This section and Figure 1-1 discuss each phase as an isolated occurrence; however, these phases overlap and blend into one another. In fact, some may occur concurrently, and the order in which they occur may vary for each patient. Concerns and needs continue to fluctuate based on the phase of the diagnosis and individualized patient and family priorities and needs.

Screening and Diagnosis

The moment of cancer diagnosis can often be met with extreme fear, anxiety, disbelief, anger, and a host of other emotions. Symptoms often precede the diagnosis, and the process of examinations, tests, and evaluations can be just as frightening. Uncertainty and anxiety can be tremendous during the diagnostic period—perhaps even higher than when a cancer diagnosis is made (Liao, Chen, Chen, & Chen, 2008). In fact, the term scanxiety has emerged to describe the fear patients
go through surrounding radiologic testing or scans for cancer (Feiler, 2011). Although scanxiety is usually reserved for survivorship screening, it is applicable for any phase (and type) of testing for cancer. Focusing on the prediagnosis phase, the patient has hope that the symptoms mean something other than cancer, that
the resolution of the problem is a simple one, that this period is merely a hiccup of uncertainty along life’s path, and that life will resume as “normal” in a relatively short time. In other cases, the patient experiences few or no symptoms, and the cancer diagnosis occurs through routine screening or as an incidental finding when dealing with another health issue. Whatever precedes it, the cancer diagnosis can replace hope with despair. More frequently, though, cancer can now be considered a chronic condition and one with which the individual can live a full life. It is important to note, however, that life after cancer diagnosis will never be the same as life before diagnosis. Residual symptoms, frequent screenings, psychosocial adjustments, and even financial challenges due to healthcare needs can significantly alter the lives of patients and their loved ones.

Throughout the diagnostic phase, many theories, models, and concepts can be applied to help the patient through this anxiety-inducing process. Using biobehavioral and systems biology approaches can help with understanding the underlying process of the disease, its sources, and consequences on a holistic level. Clinical reasoning and decision making come into play in terms of directing diagnostic tests based on patient presentation. Caring cannot be overemphasized or absent in any phase. This is also a key point at which patient–provider relationships can begin forming with strong emphasis on communication and trust. Culture, resilience, self-help, and mind–body strategies are also important considerations. Overall, the diagnostic phase of the cancer experience is the springboard to a life-changing event if cancer is found. Nurses who provide understanding and empathy can be a tremendous support in guiding patients through this phase.

**Treatment Decision Making, Planning, and Administration**

As soon as the cancer diagnosis is confirmed, treatment decisions need to be made, followed by planning and treatment administration. Treatment decision making is a shared process between the patient and provider. The provider will discuss treatment options and may make recommendations, but ideally the patient will make treatment decisions based on weighing the factors of prognosis, survivability, treatment involvement, treatment-related symptoms, and quality of life with the guidance of the healthcare team. The degree of involvement can vary, and some patients prefer to leave decisions up to the healthcare provider. One study, for example, found that most patients preferred a collaborative role with their healthcare provider in treatment decision making, compared to the minority who preferred either a passive role in letting the provider make the full decision or the patient making the decision in the absence of the provider recommendation (Hubbard, Kidd, & Donaghy, 2008). Some diagnoses do not have exact treatment guidelines; therefore, treatment recommendations cannot always be clearly defined. In patients with prostate cancer, for example, different therapies can have the same prognostic outcome but varied side effects, and the patient must weigh benefits and risks. The oncologist can evaluate the tumor characteristics, the patient’s health at the time of diagnosis, and the prognosis and make recommendations based on those parameters; however, the oncologist must consider the patient’s health-related quality of life needs in the decision-making process (Singh, Trabulsi, & Gomella, 2010). This type of individualized care can support patient autonomy and offer a sense of control. Individualized care is especially imperative when patients are in advanced stages of cancer (Peppercorn et al., 2011). Improved prediction models
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from biomarker assessment are beginning to influence treatment decisions (Burke, 2016). This is likely to be greatly enhanced through genomic sequencing, which is predicted to become a mainstream assessment tool within the next decade. Optimizing quality of life for the patient at whatever level can be achieved and doing so with as much clinical information as possible is paramount.

Once treatment decisions have been established, the planning phase begins. The healthcare team will coordinate delivery of the therapy and related activities while the patient must start to plan life around the impending treatment schedule. Additionally, once treatment begins, life can further change when symptoms present. Even with the best planning, unanticipated events can occur. During these phases of treatment decision making, planning, and administration, as in other phases, many theories, concepts, and models can drive nursing practice as shown in Figure 1-1. Through each of these phases, nurses are an essential support system and advocates who play a pivotal role in helping patients reach an informed decision. The nurse practitioner is often in the role of healthcare provider, prescribing treatments and assessing tolerance to the treatment, side effects, and clinical response. Working with patients through this process requires a solid driving force of the theories for the most successful patient experience.

**Outcome Planning**

Treatment completion is a time for celebration. Concurrently, new fears and anxiety often emerge. Waiting for confirmation that the treatment has eradicated the cancer can be an anxious time. Once confirmed remission has been established, discharge planning, including follow-up, continued or new post-treatment medication plans, and return to life, can be daunting. Often, patients will be able to continue their lives with minimal disruptions. In other cases, hospitalization removes patients completely from their home life for long periods of time. In both situations, separation anxiety from the healthcare team can ensue.

When post-treatment evaluation reveals that the cancer has not been fully eradicated, treatment decisions must be made again. If the choice is made for active treatment, the cycle of treatment planning through outcome assessment begins again. In other cases, a poor prognosis may warrant discussions about palliative and hospice care. In either situation, understanding and support from the healthcare team are crucial.

Entering remission or completing adjuvant therapy is a relief for someone going through the cancer experience. Many challenges can present themselves, however, as patients and their loved ones try to reenter a new form of normal life. Physiologic and psychological challenges can persist long after the treatments end (Recklitis, Sanchez-Varela, & Bober, 2008). Additionally, reentering routines, such as returning to work, can be difficult and stressful and necessitates a supportive and understanding environment from employers—something that is not always in place (Tighe, Molassiotis, Morris, & Richardson, 2011).

Long-term survivors face a separate set of psychosocial challenges: constant fear of cancer recurrence, being labeled as having had cancer, and various work and social stressors (Foster et al., 2009). Cancer can now be characterized as a chronic disease with so many individuals obtaining full-life survival (Berlinger & Gusmano, 2011; Lage & Crombet, 2011). Even in situations where cancers cannot be cured, patients can often be treated or managed over long periods of time. Furthermore,
patients with advanced cancers can also live longer because of new and emerging targeted immunotherapies (Cortinovis, Abbate, Bidoli, Capici, & Canova, 2016; Curtis, Cohen, & Kluger, 2016).

Living longer with cancer or in remission, however, can be compounded by comorbidities that are common in aging and by prolonged symptoms from the cancer and treatment experience (Lage & Crombet, 2011). Symptoms can persist for many years into remission (Miaskowski et al., 2014; Wright et al., 2015). Aside from ongoing worry and fear, chronic physical symptoms can be burdensome. Fatigue, for one, has been reported to be one of the most taxing symptoms and can persist for years following cancer therapies (Wright et al., 2015). Nursing care can provide immense support for patients with a history of cancer. Among the many theories and frameworks that can drive nursing practice at this stage, caring and symptom management may be paramount for many patients.

**Palliative Care and Hospice Care**

Palliative care encompasses many theories and models discussed in this chapter. Underlying theories, concepts, and models that highly support the end-of-life component of palliative care include biobehavioral and systems biology models, caring, patient–provider relationships and communication, symptom experience, culture, and mind–body strategies. In addition, Lazarus and Folkman’s theory of stress and coping can be applied to patients and family caregivers when dealing with advanced cancer (Thomsen, Rydahl-Hansen, & Wagner, 2010). Thomsen et al. (2010) showed that at stages of advanced cancer, the areas of meaning, support systems, minimizing the impact of cancer, physical and mental function, control, uncertainty, and emotions were most important to patients. The stress and coping theory, incorporating the processes of stress, appraisal, and coping, ties together stressful factors (in this example, advanced cancer and poor prognosis), the environment, and coping mechanisms (Thomsen et al., 2010). Meeting patients’ and their loved ones’ needs through understanding their process of assimilating and adapting to the changing situation can be tremendously supportive. In this context, patients can live out the remainder of their lives not only in comfort, but also with a sense of self, autonomy, and completion.

When a patient reaches a terminal illness stage where active cancer treatment is no longer an option, hospice care can provide extensive comfort measures. Although historically described in the literature in the context of end-of-life care for advanced cancer (Daland, 1948), palliative care still fits within this domain of comfort care but is now not exclusive to end-of-life care. The parameters of palliative care have shifted from an end-of-life focus to one that includes all phases (Coelho, Parola, Escobar-Bravo, & Apóstolo, 2016). Ferrell and Virani (2008) provided a comprehensive overview of national guidelines for palliative care and the role of the nurse in incorporating them. Through this seminal work on palliative care at City of Hope, many institutions have adopted the process of providing this new paradigm in palliative care for their patients. The Joan Karnell Supportive Care Program at Pennsylvania Hospital, for example, enrolls some patients from the time of early diagnosis of a life-threatening illness (Granda-Cameron, Viola, Lynch, & Polomano, 2008). Emphasizing the expansion of palliative care, the American Society of Clinical Oncology defined *palliative care* as “the integration into cancer care of therapies to address the multiple issues that cause suf-
ffering for patients and their families and have an impact on the quality of their lives” (Ferris et al., 2009, p. 3055). The World Health Organization has an even broader view of palliative care that includes multiple aspects of physical, psychological, and spiritual domains and includes the impact on patients and their loved ones (Borasio, 2011).

Hospice care, on the other hand, is reserved for those who do not have an increased chance of long-term survival through further cancer treatments and have limited life expectancy. Although numerous emerging therapies show great promise for extending life in those who had no chance for a long-shot therapy only a decade ago, many patients reach the stage when end of life is imminent. The decision to transition into hospice care can be a difficult one, filled with new levels of fear and anxiety. The element of hope is transformed into end-of-life priorities that can be identified and addressed, including existential concerns. Comfort measures should already be in place through palliative care. Quality of life is also redefined, although it certainly can be optimized at a new level of meaning. To facilitate the need, understanding, and implementation of both palliative and hospice care in earlier stages than they are often initiated, the American Society of Clinical Oncology in collaboration with the National Cancer Institute created the Education in Palliative and End-of-Life Care for Oncology (EPEC-Oncology) curriculum (Ferris et al., 2009).

### Family Caregiver Experiences

Although the focus of cancer is usually on the patient, the family caregivers of the patient undergo significant life alterations themselves. They can easily lose their own sense of self-care while focusing attention on and providing care to the patient. Family caregivers can even feel a sense of guilt if they do things for themselves while their loved one experiences the cancer process. Family can also incur stress from financial burdens of the illness in addition to overall life disruption. The risk for psychological impact on family caregivers is tremendous (Rumpold et al., 2017). Dovetailing family stress from dealing with their loved one’s illness is the potential increased risk for cancer because of genetic predisposition (Mai et al., 2011). In addition to the major genetic mutations that are well known, such as \textit{BRCA1} and \textit{BRCA2}, multiple other mutations that can increase the risk of cancer have been discovered (Kwong, Chen, & Shin, 2016); therefore, it is imperative for family members to know of this familial predisposition, be proactive with regular screenings, and ensure their healthcare providers know of the history.

The healthcare community has recognized and acknowledged the role of family caregivers as a vital part of the experience for individuals with cancer in addition to the extreme stress placed on them compounded by their own potential increased risk of cancer. Healthcare provider support for family caregivers, particularly during end-of-life care, should include strong communication, advance care planning and decision making, homecare support, empathy, and grief and bereavement (Ferris et al., 2009). Oncology nurses especially can be a support system for family caregivers with an emphasis on establishing relationships with family caregivers and actively working with them to address their concerns (McLeod, Tapp, Moules, & Campbell, 2010). Underlying theories, models, and concepts supporting family caregiver care include caring, culture, resilience, self-help, mind–body strategies, and survivorship.
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Summary

Concepts, theories, and models are essential components that drive oncology nursing practice. Through the many complex facets of care from a cancer diagnosis through long-term survival or end of life, the oncology nurse is at the heart of patient care and support for family and caregivers. The concepts, theories, and models highlighted in this chapter can form a foundation for oncology nursing practice. It is also prudent to note that because nursing has an autonomous quality, nurses may gravitate toward some theories more than others, and indeed, many theories can be incorporated into various aspects of care beyond how they are outlined in this chapter.

Theories are built on concepts, or the formation of ideas that developed from certain observations. Theories add meaning to scientific findings and are used to develop operational definitions that, in turn, are used for the development and refinement of research, education, and practice. Making this tangible, a model illustrates the related concepts that describe a specific theory, clarifying the symbolic representation. Hypotheses, in turn, can test and refine the theory or a question based on the theory and concepts. In practice, oncology nurses apply these models to enhance many aspects of patient care. Practice also guides the development of theory as nurses continually learn from their patients, creating new concepts that can evolve into theories. Nurses can create and test hypotheses about new theories and illustrate the process through visual models that, in turn, can be used to drive practice. Through this process, key variables are tested that oncology nurses can be sensitive to in practice. This fluid process enhances patient care. Whether nurses are caught up in the moment of an acute event or planning long-term care for patients with cancer, concepts, theories, and models are essential to the process.

As the platform on which nursing practice, health care, and research are based, these concepts, theories, and models serve to guide and direct decisions from acute to long-term care. Particularly in oncology nursing practice, with the many complexities that are threaded throughout the various phases of care and in which partnering with the patient and family is integral to all aspects of care, this platform cannot be overemphasized.

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