Being adequately prepared for an experience such as cancer empowers patients, lowers distress, improves coping, supports self-management, promotes recovery, and improves quality of life. However, patients with cancer report unmet informational and support needs across the cancer trajectory. The purpose of this article is to describe the relationship of information preparation and patient outcomes, identify information and support needs across the cancer trajectory, and describe the role of oncology nurses in the delivery of high-quality patient-centered cancer care. The middle range theory of "Carrying On" was used to identify information and support needs during different phases of the cancer trajectory from treatment to survivorship. The authors concluded that nurses should engage the patient in a relational exchange of information; provide concrete, understandable information across specific times in the cancer experience; and use creative approaches to minimize barriers in meeting patient needs to achieve high-quality patient-centered cancer care.

Information Preparation and Patient Outcomes

The early seminal work of Rhetaugh Dumas and Jean Johnson at the School of Nursing at Yale University (Dumas & Johnson, 1972; Dumas & Leonard, 1965; Johnson, Johnson, & Dumas, 1970) showed that nursing interventions designed to adequately prepare patients for surgery resulted in improved outcomes. Being prepared for an experience empowers patients, decreases distress, improves coping ability, supports self-management, promotes recovery, and may improve adherence and quality of life (Bennion & Molassiotis, 2013; Husson, Mols, & van de Poll-Franse, 2010; Knobf, 2002; McCorkle et al., 2011; Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004). The type of information provided is critical to how a patient copes with the experience. Whether the nurse is preparing a patient for a diagnostic procedure, surgery, radiation, chemotherapy, or a specific symptom experience, concrete objective information that includes sensory (e.g., what will it feel like) and temporal (e.g., when will it begin, how long will it last) components is essential to patients’ ability to interpret and cope with their actual experience (Johnson, Fieler, Jones, Wiasowicz, & Mitchell, 1997). Patients want information that they can easily understand (Hodgkinson et al., 2007; Myers, 2012) and they want to know what to expect (Skalla et al., 2004) and how to manage symptoms ( Gülser, Tasci, & Kaplan, 2012; Jefford et al., 2008), as well as be given information at specific times during the experience (Halkett et al., 2010; Papadakos et al., 2012; Rutten, Arora, Bakos, Aziz, & Rowland, 2005), particularly information that matches their individual needs (Halkett et al., 2010; Husson et al., 2010).

To address the ongoing unmet informational needs of patients with cancer, healthcare providers must go beyond a unidirectional provision of information from the clinician to the patient to...
improve coping and health outcomes. A patient-clinician communication framework has been proposed for oncology that identifies six core overlapping functions that contribute to high-quality cancer care and health outcomes: fostering patient-clinician relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling self-management (Epstein & Street, 2007). That framework explicitly addresses unmet informational needs by suggesting provision of information as a relational exchange that occurs between the patient and clinician and includes active listening; attention to patient preferences; and promotion of patient participation, empowerment, and self-care. The framework is very consonant with the philosophy and disciplinary perspective of nursing. However, oncology includes the challenge of providing the most current information because of dynamic discoveries in basic science, new targeted molecular therapies, genetic and genomic information, advances in diagnostic techniques and use in practice, system barriers (e.g., time, resources, staffing), emerging long-term and late-effects of curative intent therapy, and growing ethnic diversity. Descriptive published research of patient experiences often lags behind new and fast-emerging therapies in clinical practice. Communication of oncology nurses across cancer specialty practices and resourcefulness to gain the most recent information and evidence to support effective information exchange between the patient and nurse are essential to high-quality patient outcomes. To help readers understand the complexity of the experience in the context of the individual patient’s life, this article will integrate patient informational and support needs as patients transition across the cancer trajectory.

Patient Responses and Behaviors Across the Cancer Trajectory

A middle range theory, “Carrying On,” was generated from a grounded theory study of women diagnosed with breast cancer (Knobf, 2002). The theory of Carrying On has been broadly supported and adapted in the literature to encompass patient response to the problem of vulnerability related to the diagnosis, treatment, and sequelae of cancer therapy since its publication in 2002 (see Figure 1). The theory includes four process stages: being focused, dealing with uncertainty, developing awareness, and balancing. The first stage, “being focused,” reflects time in treatment and progresses to the next stage. The other three stages may progress in a linear fashion for some patients, but dependent on the symptom profile, level of patient-clinician communication, degree of information and support needs that are met or unmet, and context of the individual’s life, the patient may engage in behaviors that overlap these stages (see Figure 2).

Being Focused

The initial stage occurs when the patient experience and treatment begin. It reflects a crisis response and early adaptation to the reality of a cancer diagnosis and treatment. The stage is a time of new information, new providers, the need to learn a cancer vocabulary and medical acronyms, and dealing with the complexity of the healthcare system and oncologic therapies. Many patients are overwhelmed by the amount of information, while needing that information to manage therapy risks and side effects. Managing everyday life is characterized by being on “automatic pilot” (LaTour, 1996, p. 133) and “doing what I have to do” (Knobf, 2002, p. 11) to get through the treatment and deal with life at home. Women with breast cancer have identified feelings of social isolation during this time as they focus on their treatment requirements and everyday life tasks (Browell, Gaston-Johansson, & Danielson, 2006). Enduring has been described as a state of suspended emotion that intensely focuses on the present (Morse & Penrod, 1999). It is the way a person responds to a physical or psychological crisis and the way a person’s energy and consciousness are focused on maintaining control while getting through the situation. The concept of enduring is critical to nurses’ understanding of patient behaviors during the crisis stage in the cancer journey. Nurses must be mindful

![Figure 1. Carrying On: A Middle Range Theory of Patient Responses Along the Cancer Trajectory](image-url)

Note. Culture is perceived as transcending the entire experience.
that how an individual patient endures in this stage will be influenced by the severity of the symptom profile, level of support, quality of patient-clinician communication, therapy-related complications, and sociodemographic characteristics.

Dealing With Uncertainty

Information and communication are key factors in how patients cope with uncertainty throughout the cancer trajectory. Higher levels of uncertainty and distress are associated with inadequate information, lack of understandable information, one-way communication (clinician to patient), and lack of routine symptom assessment during and after therapy, specifically discussing what symptoms are most distressful to the individual. An ongoing need exists to make the information provided understandable to the patient, as captured in this quote related to preparation for cognitive changes, “Does it mean that I’ll roll over in bed one morning and not recognize my husband? What does it really mean?” (Myers, 2012, p. E37). The need to know what to expect remains unmet for patients, as demonstrated by patients saying things such as, “I wished she [nurse] could recognize that this was brand new to me . . . would have liked her to say, ‘Okay this is what we are going to do’” (Turkman, 2012) and “I would have loved somebody to say, ‘Radiation is going to be this, this, and this’” (Halkett et al., 2010, p. 544). Being unprepared for symptoms leads to increased distress, higher levels of uncertainty, and confusion about attribution of symptoms, and results in poorer coping and adjustment (Bennion & Molassiotis, 2013; Johnson et al., 1997; Knobf, 2008; Lowe & Molassiotis, 2011; Nail, Jones, Guiffre, & Johnson, 1984). Relying on one’s self for interpretation of unexplained or unanticipated symptoms can lead to more emotional distress, feelings of loss of control, and ineffective symptom management (Knobf, 2008). In contrast, if a patient receives concrete, objective, and understandable information about potential or actual symptoms, coping, adjustment, and self-management will be enhanced (Johnson et al., 1997; McCorkle et al., 2011; Schulman-Green et al., 2012).

Developing Awareness

This stage occurs after treatment is completed and is characterized by a gradual acknowledgement and understanding of the scope of the cancer diagnosis and the effects of treatment. The behaviors associated with this transitional stage include exploration of the meaning and significance of what has occurred, recognizing the reality of living with persistent symptoms, managing symptoms, and facing the challenges of integrating the experience into one’s life (Klimmek & Wenzel, 2012; Knobf, 2002). Unlike the first stage of “being focused,” this stage is filled with emotions. Anxiety, heightened fear of recurrence, increased uncertainty, feelings of abandonment from providers, and feeling as if they are on their own are common after treatment (Armes et al., 2009; Harrison, Young, Price, Butow, & Solomon, 2009; Lethborg, Kissane, Burns, & Snyder, 2000; Oxlad, Wade, Hallsworth, & Koczwara, 2008; Thewes et al., 2012). Exploring meaning is the beginning of a cognitive and emotional acknowledgement of what has transpired. In the early work of Weissman and Worden (1976), the first 100 days after a cancer diagnosis were described as a period of existential plight. However, the time period of that study predated current multimodality and adjuvant therapy approaches. More recent data on the emotional responses of patients following therapy suggest that a similar existential plight occurs in the subsequent months after the end of treatment, with anxiety and fear of recurrence identified as common contributors of psychosocial distress (Cappiello, Cunningham, Knobf, & Erdos, 2007; Lee, 2008; Thewes et al., 2012). Others have characterized the stage as a “crash and burn phase” (LaTour, 1996, p. 134) or a conversion from darkness to light (Taylor, 2000), indicating a gradual recognition of having lived through a violent experience and survived it, like a phoenix arising from the fire and ashes (Jagielski, Hawley, Corbin, Weiss, & Griggs, 2012; LaTour, 1996).

Facing the reality of living with persistent symptoms that may or may not resolve is inherent in this stage, as captured in a breast cancer survivor’s experience with menopausal symptoms, “After coming off chemo, I expected to feel better, but the hot flashes . . . it has been three years” (Knobf, 2008, p. 391); a survivor of colorectal cancer’s experience with bowel problems, “Nobody told me I was going to put on weight and have bowel irregularities. I also did not know that I had to learn about foods I could or could not eat. I had to educate myself” (Baravelli et al., 2009, p. 103); and a breast cancer survivor’s experience with fatigue, “The fatigue was overwhelming. I mean you expect not to feel good during treatment . . . you expect to have problems, but when you are done with treatment, you expect to get better” (Cappiello et al., 2007, p. 283). In a review of 14 studies with participants ranging from three months to five years after cancer treatment, unmet physical, psychosocial, and supportive care needs were reported by 25%–50% of respondents (Harrison et al., 2009). The stage of awareness in the initial year of the transition to survivorship also reflects a time of changing relationships (Bennion & Molassiotis, 2013). Diminishing social support is experienced from family and friends, contact with healthcare providers is dramatically reduced, and issues related to body image and sexuality begin to emerge, often affecting partner relationships (Allen, Savadatti, & Levy, 2009; Bennion & Molassiotis, 2013; Dow & Lafferty, 2000; Klimmek & Wenzel, 2012; Lethborg et al., 2000; Manne et al., 2006).

The process of recovery after therapy and transitioning to survivorship requires work (Klimmek & Wenzel, 2012). The majority of patients will cope with the challenges of getting this work done and move on as cancer survivors, often with a positive
outlook on life and establishment of new priorities (Richer & Ezer, 2002; Sears, Stanton, & Danoff-Burg, 2003). However, not all patients diagnosed and treated for cancer perceive themselves as survivors (Brennan, Butow, Marven, Spillane, & Boyle, 2011; Jagielski et al., 2012; Kaiser, 2008; Park, Zlateva, & Blank, 2009), despite the widespread adoption of the term in oncology. Some may view themselves as a person with cancer (Park et al., 2009) and cannot accept the concept of being a survivor with the reality of their feelings of anxiety and fear of recurrence. Similarly, patients post-therapy may reject the terms of returning to normal or even suggestions of creating a new normal, as they perceive themselves as forever changed by the experience and retain a heightened sense of vulnerability (Knobf, 2011).

Balancing

The balancing stage occurs after the initial work of the transitional phase (Klimmek & Wenzel, 2012) and is reported to begin a year or two after treatment ends (Knobf, 2002). Behaviors associated with this stage include being wary, finding support, struggling with the system, and keeping healthy. Being wary is a conscious effort to carefully weigh the risks and benefits of anything related to one’s health in terms of cancer recurrence or risk of chronic illness. Many survivors become medication averse, particularly those who have received chemotherapy, as captured by a survivor who said, “I stick to my naturopath—because I don’t take any medications” (Roundtree, Giordano, Price, & Suarez-Almazor, 2011, p. 1,927). Such behavior also has been characterized by breast cancer survivors as reading the fine print (Knobf, 2002), which can range from attention to medication profiles to ingredients on food products. Many survivors develop a heightened awareness of health-related issues in the media and begin to question what they are taking or should be taking, even if over the counter, such as vitamins. Providers may find it challenging to maintain a current state of the knowledge, particularly because of how time consuming it can be to acquire such knowledge. Nonetheless, if the goal is to adequately inform patients to make the best decisions for self-care, developing resources is essential to help accomplish this goal.

Finding support (informational and or social) overlaps with some of the work and behaviors associated with the early transitional phase, such as adjusting to changes in body image (Boehmke & Dickerson, 2006), adapting to persistent symptoms, and reconceptualizing one’s identity (Jefford et al., 2008; Klimmek & Wenzel, 2012), but that often is an ongoing process for many survivors. Survivors report symptoms that persist for a year or longer and interfere with self-perception and function, such as cognitive changes. As one survivor explained, “This was a really difficult thing for me because before chemo I was a great multitasker. I could work on several issues at a time. Now I find that I am unable to do that . . . makes me feel less efficient” (Cappiello et al., 2007, p. 284). Memory problems are one example of a persistent treatment effect for which limited interventions exist, and the level of associated frustration and distress for the survivor may not be appreciated by family, friends, or providers. During this time, limited provider support is received as surveillance visits decrease to once or twice a year, and patients report unmet support needs between those visits (Marbach & Grifﬁe, 2011). Little support also appears to exist to help survivors manage re-entry into relationships and social activities with others (Klimmek & Wenzel, 2012), or how to deal with the expectations of friends and family. A continuum of responses from friends and family have been identiﬁed, from protective or guarded ("you want your friend to just treat you like normal and not worry like they have to walk on eggshells or anything" [Cappiello et al., 2007, p. 287]) to expectations to return to normal and put the cancer experience behind them ("they see you walking around and they expect you to be normal . . . expectation that the person [survivor] is going to be the same, but they are not . . . unrealistic expectations from the family” [Jefford et al., 2008, p. 28]). Survivors who are younger, non-White, and those with poorer mental health functioning are reported to have more unmet informational and support needs (Beckjord et al., 2008; Knobf et al., 2012; McInnes et al., 2008).

Struggling with the system reflects patient challenges within the specialist healthcare system and the pattern of follow-up with multiple providers, which has been described as feeling in limbo with the healthcare system (Roundtree et al., 2011). Survivors report lack of coordination of care, poor communication among specialists, lack of one provider to manage care, inconsistent information and recommendations from providers, and lack of information on long-term or late effects (Baravelli et al., 2009; Brennan et al., 2011; Knobf, 2002; Marbach & Grifﬁe, 2011; Roundtree et al., 2011). Those problems can result in confusion, anxiety, uncertainty, ineffective symptom management, and increased psychosocial distress for survivors. Data are sparse on how many specialist visits per year occur, but available data suggest that survivors have regular visits to multiple specialists with no single provider offering continuity of information and care (Brennan et al., 2011; Mandelblatt et al., 2006).

Survivorship care plans have been recommended by the Institute of Medicine (Hewitt, Greenﬁeld, & Stovall, 2006), and should include a summary of the patient’s treatment; a surveillance plan; information on persistent, long-term, and late effects; and guidelines for health promotion and risk reduction. Few institutions or community oncology practices have successfully implemented survivorship care plans because they are labor- and time-intensive (Stricker et al., 2011). Only 43% of National Cancer Institute-designated comprehensive cancer centers reported providing plans, and the majority of those focused on surveillance and did not address the informational needs of survivors to support self-management (Salz, Oeffinger, McCabe, Layne, & Bach, 2012). However, patients and providers agree that written survivorship care plans offer many advantages (Baravelli et al., 2009) and can minimize or alleviate distress among survivors, as identified by one survivor who said, “If I’d have had something in writing that could have told me all the things that were going to happen I would have gone, ‘Oh, okay, alright,’ and then I could have sat down and discussed all that with my husband, but it was kind of like we were floundering and finding all these things as they happened” (Brennan et al., 2011, p. 274).
Keeping healthy is motivated by survivors’ goals to reduce the risk of recurrence, reduce the risk of comorbid illness, and reduce or manage long-term or late effects of therapy. Approaches to keeping healthy include nutrition, physical activity, use of complementary and alternative therapies (e.g., stress-reducing interventions), and managing noncancer life stressors. Challenges to keeping healthy include lack of consistent advice from providers, lack of coordination of information across providers, limited prescriptive information for healthy eating and physical activity, uncertainty of what provider to go to for what issues, and lack of expertise among oncology providers for health promotion and risk reduction (Baravelli et al., 2009; Beckjord et al., 2008; Cappello et al., 2007; Jefford et al., 2008; Knobf et al., 2012; Roundtree et al., 2011; Thewes et al., 2012; Vivar & McQueen, 2005). As one survivor stated, “I try so hard to eat well, to exercise well . . . it’s really important when you are making that effort that you’re getting the best advice . . . when it’s conflicting you just think this is too hard” (Brennan et al., 2011, p. 274).

Role of the Nurse in Achieving High-Quality Patient-Centered Outcomes

The first essential nursing intervention is to determine patient preferences for information and current understanding of the disease and treatment. This establishes the foundation for the relational exchange of information between the nurse and patient (Epstein & Street, 2007). As patients begin cancer treatment, they want to be as prepared as possible for the actual experience and anticipated or potential side effects. All patients desire information that is understandable in lay terms and provided during specific times in the course of treatment (Husson et al., 2010; Myers, 2012; Papadakos et al., 2012). However, the level of detail and need for reinforced teaching should be tailored to meet individual preferences and needs as they progress through therapy, with attention to potential unique needs based on culture, ethnicity, and age. Ongoing physical and psychological symptom assessment and documentation is a critical nursing activity throughout the entire cancer trajectory. These data are needed to establish what the patient needs to know, what symptoms are most distressful to the patient, and to determine an effective management plan with the goal of achieving high-quality patient-centered outcomes (see Figure 3). Lack of coordination of care and dissatisfaction with communication across providers, combined with inconsistent information from providers and a general lack of one key provider to manage care have been reported by patients during and following cancer therapy. Nurses are in a pivotal position within the healthcare team to address these gaps in care and advocate for a model of patient-centered care (Adler & Page, 2007; Patlak, Balogh, & Nass, 2011).

Barriers to achieving patient-centered care may include the healthcare delivery system, resistance to change among providers, resources, time, and staffing patterns. Use of technology in clinical care, assessment of the role of the oncology nurse related to patient education and care coordination, emerging emphasis on quality improvement and quality indicators, innovative Intervention research, and translation of best-available evidence to practice offer nurses opportunities to improve patient outcomes. The widespread use of technology and the increasing familiarity among people of all classes and ages provide nursing with the opportunity to creatively use technology for symptom assessment (Basch et al., 2005; Berry, 2011; Wolpin et al., 2008), patient teaching (Anderson & Klemm, 2008), and delivery of nursing interventions (Leykin et al., 2012; Syrjala et al., 2011). The electronic medical record can be used to maximize provider communication and continuity of care, and many systems include features for the patient to maintain a personal chart and receive information pertinent to their needs and directions for the plan of care. Although technology is readily available, assessing where the nurse and the patient are on the technologic learning curve, from limited user to highly innovative user, and tailoring the information exchange accordingly are important.

Delivery of oncology care reflects diverse roles for the RN and for the advanced practice nurse within and across settings throughout the patient’s cancer trajectory. Nurses need to assess the roles of nurses, communication patterns, documentation systems to support practice, physician relationships, and coordination of care in relationship to the desired quality patient outcomes. Because patients want information at specific times during treatment and survivorship, desire better communication across providers, prefer identification of a key provider for their questions and to coordinate their care, and want adequate time with nurses and physicians to discuss their symptoms and symptom management, it is incumbent on nurses to determine how those needs get addressed and met. As the majority of patients with cancer traverse multiple specialties for diagnostic procedures and treatment, nursing is well positioned to advocate and address these unmet informational and support needs within the organizational structure. Use of the electronic medical record could support communication about patients among nurses across care settings.

Conclusions

Robust data support that meeting patients’ informational and support needs empowers patients, decreases distress, increases coping ability and self-care management, and improves quality

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**Implications for Practice**

- Nurses are in a pivotal role on the healthcare team to advocate for high-quality, patient-centered care.
- Communication as a relational exchange empowers patients and enhances self-care.
- Communication and coordination of care across providers are essential to meeting patients’ informational and support needs.
of life. However, patients with cancer continue to report unmet needs along the cancer trajectory. The current article reviewed the responses and behaviors of patients as they progress on their cancer journey, providing insight and direction to the patient’s readiness and the type of information and support needed at different times during this journey. Nurses are uniquely positioned and qualified to creatively address barriers to overcome unmet patient needs to achieve high-quality patient-centered cancer care.

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