Nurses as Patient Advocates in Oncology Care: Activities Based on Literature

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This article will explore oncology nurses’ patient advocacy activities and compare those activities with patient advocacy activities defined in an earlier study by the authors. Data were collected from 42 English-language peer-reviewed articles published from 2000–2010. Search terms used included cancer care and advocacy and oncology nursing and advocacy. According to the findings of the reviewed articles, oncology nurses promote the interests of their patients by analyzing patients’ psychosocial and physical distress and care plans, particularly at the beginning of the illness trajectory. Oncology nurses also are instructed in the literature to educate patients about cancer management prior to the first treatment and during cancer management to promote informed consent, but not to analyze patients’ information or self-determination preferences. Oncology nurses do, however, advocate for their patients by presenting and raising awareness of patients’ needs and preferences in regard to the healthcare system. To some degree, this advocacy can be seen as responding to patients’ care and self-determination preferences. Oncology nurses’ patient advocacy activities are similar to advocacy activities defined in the context of procedural pain care but are more focused on the beginning of the illness trajectory. However, care and self-determination needs, information needs, and advocacy needs of patients with cancer vary during the illness trajectory. Those needs should be analyzed and responded to systematically.

At a Glance

- Patient advocacy is defined as an iterative process of analyzing, counseling, and responding to patients’ care and self-determination preferences.
- Oncology nurses’ analyzing, counseling, and responding advocacy activities should be further explored and promoted in the context of oncology nursing care.
- A need exists for a structured and validated instrument to measure information and advocacy needs of patients with cancer during different phases of the illness trajectory.

Patients with life-threatening diseases, such as cancer, have a vast range of needs varying from alleviation of emotional distress to guidance regarding self-care. The cancer treatment and care process usually includes contact with several healthcare professionals during the illness trajectory. To involve patients with cancer in decision making concerning their care, those healthcare workers must analyze and respond to patients’ information needs and self-determination preferences on an individual basis. Tailored education has been shown to correlate with improved patient outcomes (Treacy & Mayer, 2000), and involvement in decision making is a central factor in an effective and equal care process (Act on the Status and Rights of Patients, 1992).

At the beginning of the illness trajectory, patients’ information needs concern the illness, its treatment, and the prognosis (Cramer Bertram, 2008). Patients usually require educational information on treatment options put forth by a physician. However, misunderstanding this information (when provided) is common because a patient’s cognitive capacity may be compromised by the illness (Perrin et al., 2006). In addition, patients initially may
be unfamiliar with the healthcare system and lack knowledge of their rights as patients (Vaartio, Leino-Kilpi, Suominen, & Puukka, 2009) before becoming more familiar with these aspects as the process evolves (Adler & Page, 2008).

About 50% of patients with cancer are known to change their desired level of involvement during the cancer management process (Vogel, Bengel, & Helmes, 2008). However, healthcare professionals may fail to analyze patients’ evolving information and self-determination preferences and, therefore, underestimate the significance of these changes (Vaartio et al., 2009). Healthcare professionals also may have preconceived perceptions of the kind of information related to treatment or healthcare delivery that should be introduced to the patient (Cramer Bertram, 2008) and by whom, if at all (Vaartio, 2008).

During the actual cancer treatment phase, patients require education regarding informed consent for diagnostic and procedural interventions and how to best prepare themselves for the interventions. In addition, information on the side effects of treatment and guidance on how to tackle the different physical symptoms are needed at this time (Cramer Bertram, 2008). As patient advocates, nurses can further address the information and self-determination needs of their patients by fostering open communication. The task of communicating medical information given by oncologists to the patient often falls to nurses (Ziegler, Newell, Stafford, & Lewin, 2004). On the other hand, relaying messages from patients to physicians (e.g., if the patients feel that receiving information and making decisions are too tiring) also falls to nurses.

Patient advocacy has been described as raising one’s voice in favor of someone (“Patient Advocacy,” 2009), and, as a nurse, one who uses his or her role to promote and safeguard the well-being and interests of patients by ensuring that they are aware of their rights and have access to the information they need to give informed consent (“Patient Advocate,” 2008). In Vaartio (2008) and Vaartio et al. (2009), patient advocacy was described by patients (n = 405) and nurses (n = 118) as nursing activities aimed at securing patients’ legal and ethical rights and satisfying their existential needs, both on the level of the patient-nurse relationship and in the healthcare team or organization. That can be achieved by continuously analyzing a patient’s care and self-determination preferences; by counseling the patient and others involved in the patient’s care regarding these preferences; and by responding to any existential, ethical, or clinical challenges emerging during the course of the care process. These advocacy activities (see Figure 1) are discussed in this article in the context of cancer care.

Data Sources

A data search was conducted using the EBSCO Health Source and CINAHL® databases, and 56 peer-reviewed English-language articles were identified. Fourteen of the articles were excluded because they were found to be descriptions of peer advocacy or activities of ombudsmen, not oncology nurses. The final data were retrieved from the remaining 42 articles.

Data Synthesis

The authors used a deductive analysis to compare the descriptions of oncology nurses’ activities in relation to oncology nurses’ patient advocacy activities previously identified in Vaartio (2008) and Vaartio et al. (2009). In this analysis, the term nurse also comprises pivot nurses in oncology (PNOs) (i.e., nurses who accompany patients and families from the cancer diagnosis onward; assessing and managing their needs, teaching and providing information, providing support, and coordinating and ensuring continuity of patient care [De Serres & Beauchesne, 2000]), oncology nurse navigators, and OCNs®. If the descriptions of oncology nurses’ activities did not fit the authors’ classification of nurses’ activities in their capacity as patient advocates, the described activities were listed as “other patient-centered activities,” with no advocacy dimension. The results of the comparative analysis are presented in Table 1.

Results

Analyzing as an Advocacy Activity

In Vaartio et al. (2009), the analyzing activities involved in patient advocacy were defined as analyzing the patient’s care preferences and analyzing the patient’s self-determination preferences. In the reviewed articles, oncology nurses seem to analyze their patients’ care preferences through assessment of health status, quality of life, symptoms, and treatment plans, but not their self-determination preferences.

Patients’ health status is analyzed in the clinical setting by nurses using quality-of-life instruments and other corresponding measures (Davis, 2007). However, standard methods for assessing psychosocial issues in patients with cancer may not be used on a consistent basis because of nurses’ concerns with more immediate physical symptoms and the great difficulty

Figure 1. Nurses’ Patient Advocacy Activities: Iterative Process

Note. Based on information from Vaartio et al., 2009.
of assessing and addressing psychosocial issues (Buchanan, O’Mara, Kelaghan, & Miniasian, 2005; Swanson & Koch, 2010). Patients’ perceived anxiety is another theme of analysis within cancer care (Pineault, 2007). About 33% of all patients with cancer experience prolonged and high levels of distress that contribute to ongoing adjustment difficulties (Sellick & Edwardson, 2007). Therefore, discussions led by healthcare professionals are needed for all of the types of symptoms a patient may experience, not just physical ones (Detmar, Aaronson, Wever, Muller, & Schormagel, 2000). The analysis of anxiety could be completed by a PNO or an oncology nurse navigator who reviews the distress list with the patient. Using the list, the oncology nurse navigator can act as a patient liaison with various departments and agencies in an attempt to alleviate as much of the patient’s distress as possible (Swanson & Koch, 2010). That practice relies on the patient’s self-determination preferences because the patient is asked if he or she is interested in the services of an oncology nurse navigator. However, the practice is simultaneously based on the patient’s actual needs, which may vary during the illness trajectory and on the physician making the oncology nurse navigator referral.

Nurses play an important role in early identification and analysis of emerging symptoms (Fessele, 2007). They also assess and represent patients’ and families’ needs and preferences in initiating, analyzing, developing, implementing, and revising treatment plans as well as reviewing treatment recommendations with the patient (Fessele, 2007; Pavlish & Ceronsky, 2009; Wilcox & Bruce, 2010). Nurses also are seen as important assets for patients in regard to following treatment plans (Seek & Hogle, 2007). Adequate and continuous pain management, for example, requires nurses to ensure that patients are provided with prescriptions for pain medication when transitioning from hospital care to home care (Vaartio et al., 2009). In a study by Tsigaroppoulos et al. (2009), the most essential requirement of caretakers and patients at home was pain alleviation. The majority of caretakers reported that the patient suffered from pain and they, the caretakers, faced difficulty in managing it.

### Counseling as an Advocacy Activity

In Vaartio et al. (2009), counseling advocacy activities were defined with two subcategories: counseling the patient in the nurse’s care and counseling those involved in the patient’s care

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**Table 1. Results of the Comparative Analysis**

<table>
<thead>
<tr>
<th>VARIABLES</th>
<th>ANALYZING&lt;sup&gt;a&lt;/sup&gt;</th>
<th>COUNSELING&lt;sup&gt;b&lt;/sup&gt;</th>
<th>RESPONDING&lt;sup&gt;c&lt;/sup&gt;</th>
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<tbody>
<tr>
<td>Nurses’ patient advocacy in the oncology setting</td>
<td>• Assessing patients’ needs (De Serres &amp; Beauchesne, 2000; Detmar et al., 2000; Pavlish &amp; Ceronsky, 2009)</td>
<td>• Informing patients so they feel they are able to make educated decisions (Pavlish &amp; Ceronsky, 2009), assisting in decision-making (Corish, 2005), and providing the nursing staff with specific information important for patients’ health-belief systems or lifestyles (Wilcox &amp; Bruce, 2010)</td>
<td>• Responding to patients’ care preferences through symptom management (Fessele, 2007; Gapstur, 2007) and helping to develop plans that are directed by patients (Corish, 2005)</td>
</tr>
<tr>
<td>Nurses’ other patient-centered activities in the oncology setting</td>
<td>• Assessing patients’ health status (Davis, 2007) and identifying emerging symptoms (Fessele, 2007)</td>
<td>• Teaching and providing information (De Serres &amp; Beauchesne, 2000) and educating patients, families, peers, and the public so as to lower their distress related to cancer (Seek &amp; Hogle, 2007; Swanson &amp; Koch, 2010; Wilcox &amp; Bruce, 2010)</td>
<td>• Representing patients’ and families’ needs (Pavlish &amp; Ceronsky, 2009)</td>
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</table>

<sup>a</sup>Includes subcategories of analyzing the patient’s care and self-determination preferences  
<sup>b</sup>Includes subcategories of counseling the patient about his or her care and counseling those involved in the care of the patient about that patient’s care and self-determination preferences  
<sup>c</sup>Includes subcategories of responding to the patient’s care preferences and responding to the patient’s self-determination preferences
regarding the care and self-determination preferences of the patient. Those two subcategories were supported by the reviewed literature and often were achieved by educating patients and their families, promoting patients’ informed consent, coordinating patient education, and ensuring communication between caretakers and providers.

Oncology nurses are vitally involved in the education of patients, families, and the general public. Physicians inform patients of treatment plans, alternative treatments, and the risks and benefits of proposed treatments, as well as evaluate the effects of those treatments. However, patients may need detailed information on proposed treatments before feeling like they are making informed decisions (Pavlish & Ceronsky, 2009). Nurses often are able to translate complex and confusing information, such as treatment plans, into lay terminology for patients and their families (Lackey, Gates, & Brown, 2001; Wilcox & Bruce, 2010). In addition, patients may need information on side-effect management, nutrition, emotional coping, and other skills key to their care (DeSanto-Madeya, Bauer-Wu, & Gross, 2007; Leydon et al., 2000; Swanson & Koch, 2010). Inpatient staff nurses often have time only for the essentials—particularly with short hospital length of stay—and patient education may, therefore, be fragmented and incomplete. However, OCNs and oncology nurse navigators can fill that gap. Regarding distress, an OCN may be the most capable at leading a discussion and supporting the patient (Swanson & Koch, 2010). Similarly, an oncology nurse navigator can play a significant role in decreasing the distress scores of patients through education of the patient and his or her family regarding treatment goals. In addition, the oncology nurse navigator explains the anticipated process when the patient presents the first time for treatment at the hospital (Seek & Hogle, 2007; Wilcox & Bruce, 2010). An oncology nurse navigator also may act as a guide and attend all appointments with the patient until the patient is able to navigate the oncology medical system independently (Fowler, Steakley, Garcia, Kwok, & Bennett, 2006; Swanson & Koch, 2010). However, in the reviewed articles, descriptions of how and by whom this decision is made were not indicated.

Oncology nurse navigators are in a position to discuss with the healthcare team the treatment schedule for the patient, provide details on the information and education that have been provided to the patient and family, and offer specific information to support the patient’s health-belief system or lifestyle. An oncology nurse navigator also ensures communication as a patient transitions from one care setting to another (Wilcox & Bruce, 2010) by collaborating with all members of a patient’s medical team to ensure that information on the diagnosis and treatment plan is understood by all team members, including doctors, nurses, ancillary staff, and family members (Swanson & Koch, 2010). According to Campbell, Craig, Eggerd, and Bailey-Dorton (2010) and Hewitt and Ganz (2007), this education coordination function should extend to home health care and other situations (e.g., palliative and hospice care centers), including information on the type of cancer, treatments received, potential side effects, recommendations for follow-up care, and evidence-based guidelines that should be adhered to.

Responding as an Advocacy Activity

In Vaartio et al. (2009), the responding advocacy activities were found to contain two subcategories: responding to the patient’s care preferences and responding to the patient’s self-determination preferences. Those two subcategories integrate clinically, ethically, and legally relevant nursing activities and examine ethically problematic care situations and some proactive whistle blowing. In the literature reviewed for this article, nurses responded to the clinical and ethical needs of patients with cancer by representing and bridging their needs regarding symptom management based on patients’ care preferences and by promoting patients’ rights to information and comprehensive care.

Nurses represent patients with cancer by helping in the development of treatment plans that are directed by patients (Corish, 2005; Pavlish & Ceronsky, 2009). Nurses also assist patients in initiating discussions with family members and their physicians and then remain with the patients to help them make their choices either with a silent presence or, if necessary, an active voice (Corish, 2005; Davis, 2007). In other nonspecified situations, nurses relay messages to physicians on behalf of their patients and obtain answers from physicians regarding the concerns of patients or family members (Wilcox & Bruce, 2010). Nurses also can strengthen relationships between patients and their family members. When family disagreements occur, nurses attempt to resolve the communication problems by finding common ground (Pavlish & Ceronsky, 2009). Those all are typical examples of triadic advocacy in which nurses act as the mediating third party in the dialogue between the patient and someone else, representing the patient and his or her preferences.

Nurses also promote patients’ rights to information. In some cultures, patients are not informed of diagnosis because they themselves do not want to know the details or because family members wish to spare the patient (Lin et al., 2003). The decision not to disclose the diagnosis often is rooted in perceptions of what is best for the patient. Diagnosis disclosure may be avoided to minimize the distress related to the reception of diagnosis or may be based on the patient’s perceived ability to cope and the possible negative impact on adherence (The, Hak, Koeter, & van der Wal, 2000). However, evidence exists that patients’ emotional turmoil is greater when uncertainty and suspicion surround the illness (Lin et al., 2003). Both legally and ethically, nondisclosure is against a patient’s right to information and the right to participate in decision making concerning care and treatment. When patients lack full and honest information, nurses are constrained in the establishment of an effective nurse-patient relationship; this may adversely affect the quality of the nursing care delivered. A study by Kendall (2006) contained descriptions of conflicts which arise between healthcare professionals and patients’ relatives. In the study, nurses voiced strong opinions about the issues of disclosure and felt that patients’ rights should come before the wishes of relatives.

In addition, nurses promote their patients’ rights to justice in relation to health policy issues. Oncology nurse navigators are in a key position to help patients overcome barriers to care during patient transitions from one care setting to another (Wilcox & Bruce, 2010). An oncology nurse navigator also ensures communication as a patient transitions from one care setting to another (Wilcox & Bruce, 2010) by collaborating with all members of a patient’s medical team to ensure that information on the diagnosis and treatment plan is understood by all team members, including doctors, nurses, ancillary staff, and family members (Swanson & Koch, 2010). According to Campbell, Craig, Eggerd, and Bailey-Dorton (2010) and Hewitt and Ganz (2007), this education coordination function should extend to home health care and other situations (e.g., palliative and hospice care centers), including information on the type of cancer, treatments received, potential side effects, recommendations for follow-up care, and evidence-based guidelines that should be adhered to. Nurses often are able to translate complex and confusing information, such as treatment plans, into lay terminology for patients and their families.
(Swanson & Koch, 2010). Those barriers are identified as financial issues, language differences, cultural factors, healthcare system complexities, and transportation issues (Pedersen & Hack, 2010). During an ongoing cancer treatment period, questions may arise about new therapies and their availability. Davis (2007) pointed out that evidence exists of underrepresentation of older adult patients in clinical trials, and, according to Davis (2007), nurses should advocate for this population’s inclusion. Another source of disparity, which often is overlooked, is the distance to a treatment center. Lyons (2004) found that women living in rural settings had to travel greater distances for appointments and felt more isolated from their social network during the treatment phase. In addition, women in rural settings experienced more difficulty in accessing the necessary resources compared to women who lived in urban settings (Lyons, 2004).

Oncology nurse navigators can respond to such issues by assisting their patients with transportation needs and arranging schedules so fewer trips will be required for tests, treatments, or follow-ups (Swanson & Koch, 2010). Toward the end of medical treatment, nurses should work to raise awareness regarding the needs of cancer survivors, eliminate discrimination in employment of cancer survivors, and support allowances for short- and long-term limitations in the workplace as a result of the adverse effects of cancer (Morgan, 2009).

Discussion

Nurses play an important role as patient advocates in cancer care. The literature reviewed for this article showed that nurses use their role to promote and safeguard the well-being and interests of their patients. That well-being often is described in terms of health status, physiological distress, or quality of life at the beginning of the illness trajectory (but often not at later stages). Nurses also ensure that patients are aware of their rights and have access to the information they need to be able to give informed consent (“Patient Advocate,” 2008). However, the reviewed literature primarily focused on patient education, not the analysis of patients’ individual information needs, care preferences, or self-determination preferences, which vary during the illness trajectory. Therefore, although all three types of advocacy activities defined in Vaartio (2008) and Vaartio et al. (2009) are relevant in the care of patients with cancer, some subcategories are not applied systematically or across the illness trajectory.

Nurses’ analyzing activities in the oncology setting concern patients’ health status and physical distress or identifying unexplained issues that are causing patients distress. Nurses also analyze patients’ psychosocial needs, such as quality of life and anxiety levels. Those analyses are conducted to identify patients’ difficulties adjusting to the cancer diagnosis, a revision of the care plan, or for distress alleviation. However, whether nurses analyze these factors systematically or only at the beginning of the illness trajectory is unclear (Buchanan et al., 2005; Swanson & Koch, 2010). The authors believe that assessment should be incorporated into all phases of the illness trajectory to facilitate the revision of the care plan when needed. Symptom distress can interfere with a patient’s quality of life and treatment compliance and, thereby, affect patient outcomes (Swanson & Koch, 2010). The analyzing activities are only partly in accordance with the analyzing advocacy activities identified in Vaartio et al. (2009). According to the reviewed literature, the self-determination preferences of patients with cancer are not analyzed, although all other analyzing activities seem to be carried out jointly with the patients. In addition, the literature reports that patients usually are coupled with an oncology nurse navigator until the second cycle of treatment or until they are able to maneuver the oncology medical system independently.

Oncology nurses play an important role in informing and educating patients with cancer and their families, translating in lay terms the information received, promoting informed consent, and communicating with the healthcare team to ensure coordination and continuity of the treatment plan. That task is not directly connected to patients’ information needs, although motivation is related to distress alleviation, continuity of care, patients’ rights to information, and patients’ education about informed consent. Education content mainly is concerned with the biophysiological aspects of the illness and medical treatment; however, patients with cancer also need counseling on functional, empirical, social, ethical, and economic aspects of life (Cramer Bertram, 2008; Thomas, Kaminski, Stanton, & Williams, 2004). Nurses should systematically assess the information needs of patients with cancer (Sutherland, Hill, Morand, Pruden, & McLachlan, 2009); however, few research reports examine how nurses should go about assessing these needs (Sutherland et al., 2009). In addition, only a few instruments have been developed for the purpose of measuring information needs, and the instruments do not consider the phase of illness trajectory.

The European Organisation for Research and Treatment of Cancer questionnaire (Arraras et al., 2004) aims to evaluate the information received by patients with cancer and the impact of this information on their quality of life. The focus of this instrument is in biophysical issues, as is also the case in the Patient Information Need Questionnaire (Mesters van den Borne, Maarten De, & Pruyn, 2001). In the Toronto Informational Needs Questionnaire, the subscales include disease, investigatory tests, treatments, and physical and psychosocial items (Galloway et al., 1997), but no complications and financial or ethical issues. The Supportive Care Need Survey (Boyce, Girgis & Lecathelinais, 2009) includes five domains, one of which concerns the information needs of adult patients with cancer. The Information Satisfaction Questionnaire (Thomas et al., 2004), which focuses on information satisfaction of the patient, also is a useful instrument.

Patients’ self-determination preferences are not measured in any of the aforementioned instruments. In addition, all of the instruments are designed for application at the beginning of the illness trajectory, with the exception of the Patient Learning Needs Scale (Galloway, Bubela, McKibbon, McCay, & Ross, 1993), which is used at discharge alone. The instruments do not sufficiently consider the particular phase of illness trajectory or the different individual factors related to information needs. Therefore, the educative task of oncology nurses identified in the reviewed literature reminds the authors of the advocacy activity of counseling patients about their care (Vaartio, 2008); however, the educational information given is not the same as answering patients’ individual counseling needs concerning their own care. Nurses also are reported to share with the
healthcare team specific information important to supporting the patient’s health-belief system or lifestyle. This can be regarded as an advocacy activity regarding counseling those involved in the care of patients about the patients’ care and self-determination preferences.

According to the reviewed literature, nurses responded to their patients’ care preferences by means of symptom management (Fessele, 2007; Gapstur, 2007). In addition, the nurses presented the needs of their patients to a healthcare professional empowered to make decisions. These bridging advocacy activities involve patients’ legal and moral rights to information and participation in decision making concerning their own care. In addition, nurses also aim to advance equality of care by helping patients overcome barriers to care (Pedersen & Hack, 2010), raising awareness of adverse events, or initiating a change in healthcare policy (Davis, 2007). Triadic advocacy is evident in oncology settings, with emphasis placed on the power and importance of a medical treatment plan and on nurses’ ethical competence.

In the reviewed literature, the use of an oncology nurse navigator was proposed as a method to improve patients’ care or as a way to guide patients through cancer management healthcare organizations. The oncology nurse navigator’s task is to connect patients and families with available resources by providing information, facilitating continuity in the domain of cancer care, improving patient outcomes, and ameliorating the overall quality of healthcare delivery (Pedersen & Hack, 2010; Seek & Hogle, 2007). Navigators share the goal of patient advocacy by promoting patients’ rights and the way of doing it: with the patient, not for the patient. However, those concepts are not synonymous because patient advocacy is a part of patient-nurse relationship and the ethically and clinically sound care process (Vaartio, 2008), whereas the navigator (and ombudsman) is a person outside the care process, usually in the outpatient setting (Campbell et al., 2010) but still affecting the care process, with an aim to shorten the time to the initiation of cancer treatment, to increase cost-effectiveness, and to improve satisfaction with care.

Limitations
Some limitations may have affected the findings of this review. The keywords are strictly delineated into certain concepts and, therefore, some aspects of practical patient advocacy in the oncology context may remain excluded. However, the aim of this review was not to describe oncology nurses’ advocacy activities, but to test the authors’ earlier definition of nurses’ advocacy activities.

Implications for Nursing
Oncology nurses should develop patient advocacy activities by systematically analyzing the individual information needs of patients and their care and self-determination preferences during the whole illness trajectory. That would lead to promotion of well-being and patient rights, as well as the continuity and excellence of nursing care. An obvious demand exists for a structured instrument for measuring the information needs of patients with cancer during different phases of the illness trajectory. A demand also exists for additional exploration of nurses’ methods of analyzing and responding to these needs, and of patients’ needs for an advocate related to the role of nurse navigator.

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