The NCCN Guidelines Program and Opportunities for Quality Improvement

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Clear evidence is available regarding the wide variation in the quality of cancer care delivered in the United States. These findings led the Institute of Medicine (IOM) in 1999 to call for major changes in cancer care delivery to improve quality and enhance the patient experience.¹ Key domains for the recommendations included steps to define appropriate quality care, identify appropriate measures of care, establish mechanisms to collect and analyze cancer treatment information, and assure that care addresses overall needs of patients beyond the core processes of treatment. Despite major changes in medicine, and with the continued and rapid increase in the cost of cancer care, the IOM reiterated their findings in 2013, stating that there exists a crisis in quality, appropriateness, and access to cancer care.²

One of the key efforts in the United States to address quality of care has been the development of comprehensive guidelines for oncology practice by NCCN.³ First published in 1996, the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) cover virtually all types and stages of cancer and cover many areas of supportive care. The guidelines are updated at least annually, and more rapidly when key new findings are evident. NCCN Guidelines are widely used as a benchmark of the best standard of care in the United States, and have been adapted for use around the world.⁴⁻¹⁰

NCCN Guidelines and the NCCN Oncology Outcomes Database Program

In 1996, NCCN leaders recognized that the NCCN Member Institutions should use these guidelines to examine the care they provide to assure and continually improve the quality of that care. This led NCCN to establish a system for collecting information to determine if the care was consistent or “concordant” with the relevant portion of the guidelines. They founded the NCCN Oncology Outcomes Database in 1997 to examine breast cancer care at 5 centers.¹¹,¹² Over the ensuing years, the NCCN Oncology Outcomes Database expanded to other centers and to include non-Hodgkin's lymphoma and lung, ovarian, and colorectal cancers.

The database was initially used to evaluate the quality of cancer care, defined by concordance of treatment for each key phase of care (eg, surgery, radiation, systemic therapy) with the guidelines. Starting in 1999, each participating institution was provided an annual report of concordance for all patients. The NCCN Oncology Outcomes Database has also been used extensively for reporting on patterns and quality of care at NCCN centers and to examine factors influencing treatment choice and outcome, with numerous high-impact publications.¹³⁻¹⁷

NCCN did not initially set specific standards or levels of required concordance or require specific actions to be taken based on these reports. Concordance findings were provided to each center annually, but the center was left to use the data as they saw fit. No collective review or coordinated action was taken to address the findings. Indeed, no determination was made regarding what level of guideline-concordant care was considered “high-quality” care. Guideline concordance is not expected to be 100%, because any clinical situation may involve circumstances (eg, coexisting illnesses, patient choice) that result in selection of nonconcordant therapy.
Several institutions conducted a detailed review of all nonconcordant care and showed that about half of the instances of “nonconcordant” care was due to clearly documented medical circumstances and half to patient choice; relatively few cases were related to missed or inappropriate care.\textsuperscript{18,19} However, beyond treatment concordance, the database revealed substantial variation in care among institutions, especially in situations for which no high-level (eg, randomized trial) evidence or conflicting evidence exists. In many studies of practice patterns at NCCN centers, care varied widely among institutions. For example, the rate of breast-conserving surgery among NCCN Member Institutions for stage I breast cancer ranged from 40% to 85%. The use of chemotherapy for hormone receptor–positive breast cancer varied widely, as did use of radiation after mastectomy.\textsuperscript{13,17,20}

The degree of variation in care among centers suggested that opportunities existed to reduce variation, examine key internal processes, and improve the care provided at NCCN centers. Therefore, in 2009, under the leadership of Dr. Jane Weeks, representatives of the institutions participating in the NCCN Oncology Outcomes Database for Breast Cancer met and reviewed in detail the findings from each institution. The group specifically discussed areas with a wide variation in care and agreed that a coordinated effort to address the variation in care among NCCN centers was warranted.

**Opportunities for Improvement**

Based on this meeting, NCCN initiated the Opportunities for Improvement (OFI) project. Centers participating in the breast outcomes database were invited to participate in this project, in which they would identify and address quality issues in breast cancer treatment within their centers. Each center was provided data on guideline concordance and information on time to treatment based on information from the outcomes database. A project team at each center reviewed these findings and established a program “charter” that outlined a specific plan to address quality issues within their breast cancer treatment system. Periodic teleconference meetings and written progress reports assured progress on stated goals and new areas of focus that developed from the review.

This supplement to JNCCN includes the final reports from each of the NCCN centers participating in the OFI project. The reports illustrate the range of opportunities for quality improvement in large multidisciplinary practices. Although the charter and objectives of each group were unique to each institution, clear themes are evident.

Institutions were expected to focus on mechanisms to improve concordance with the NCCN Guidelines for Breast Cancer in areas reflecting a low level of concordance. Several institutions addressed specific areas of guideline concordance, such as initiation of endocrine therapy after the recommended time frame following radiation because of barriers to patient flow inside the institution, and the use of bisphosphonates among patients with metastatic breast cancer. However, most of the centers determined that much of the care that was not concordant with the guidelines recommendation was due to physician judgment or patient choice. Therefore, most centers focused on other quality issues.

Several institutions focused on barriers to efficient and timely patient care. The work groups developed under the OFI charter provided a multidisciplinary platform to engage patients and caregivers at all levels to identify and address these barriers. To measure the impact of their efforts, most centers used the time between different components of treatment, such as time from initial diagnosis to consultation or initial surgery, or time from surgery to adjuvant therapies, as defined by the NCCN Oncology Outcomes Database.\textsuperscript{21,22}
Time to treatment may be an important measure of the performance of a cancer program. Delays in treatment, and disparities in delay have clearly been described in hospital and population cohort studies.\textsuperscript{23–25} In these studies, most individuals receive treatment within time frames generally believed to have no impact on overall cancer outcome. However, delays compounded by repeated delays with successive provider specialties over the course of the typical sequential referral of cancer treatment could have potential negative consequences on outcome.\textsuperscript{26} Furthermore, delays in treatment may have a significant impact on patient satisfaction and well-being.\textsuperscript{27} Addressing these delays may have an impact on these outcomes, the patient experience, and the market-competitive performance of a cancer program.

Concern regarding delays in treatment is not new or limited to the United States. Delays may be caused by patient, primary care diagnostic, or cancer care system issues, with delays within the care system being a significant issue in United States and United Kingdom.\textsuperscript{28} Delays in treatment became so significant in the United Kingdom that the National Health Service set standards for time from diagnosis to initial consultation.\textsuperscript{29,30} The standards call for consultation regarding suspicious breast findings within 14 days, a maximum 1-month wait from diagnosis to treatment, and maximum 2-month wait from urgent general practitioner referral to treatment for all cancers.\textsuperscript{30} Hospital compliance rates with these standards are provided to the public.

The articles in this supplement provide insights into the collective wisdom at the participating NCCN centers regarding the best target areas for improving care and the patient experience. These efforts may help other programs define targets for practice evaluation and continuous quality improvement. These key efforts are necessary to improve cancer outcomes and experiences, and will be necessary in the coming era of public quality reporting and value-based reimbursement.\textsuperscript{31}

References


