Coordination of Care for Early-stage Breast Cancer Patients

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OBJECTIVE: Little is known about how care is coordinated for patients with diseases requiring multidisciplinary treatments. How complex care is coordinated may affect a patient's chance of receiving the full complement of care provided by multiple physicians. We sought to describe approaches used to coordinate care for women with early-stage breast cancer, a disease often treated by multiple different disciplines in the outpatient setting.

DESIGN: Case studies of 6 hospitals with in-depth semi-structured interviews with providers of breast cancer care and their support staff.

SETTING: Five hospitals in downstate New York and 1 hospital in upstate New York.

PARTICIPANTS: Sixty-seven interviews were conducted including 35 physicians, 9 nurses, 4 senior clinical or quality directors, 10 administrative assistants, and 9 patient educators and navigators.

MEASUREMENTS AND MAIN RESULTS: Content analysis of interviews revealed 7 different coordination mechanisms including tracking of referrals, patient support, regularly-scheduled multidisciplinary meetings, feedback of performance data, use of protocols, computerized systems, and a single physical location. No site had any systematic mechanism to track results of referrals or receipt of care provided by other physicians. All physicians used follow-up appointments to check on patients' receipt of care, but only half of the physicians had an approach to follow up missed appointments. Real-time multidisciplinary meetings with a patient management focus and systematic use of patient support programs, such as patient educators and navigators, were perceived to be valuable.

CONCLUSIONS: Numerous coordination mechanisms exist. No site has the ability to systematically track care provided by multiple different specialists. The most valued mechanisms are under the hospital's aegis. Hospitals should consider implementing coordination mechanisms to improve delivery of multidisciplinary care.

KEY WORDS: coordination; breast cancer; quality of care.
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Most of the nearly 200,000 women who will be diagnosed with breast cancer in the coming year will

have early-stage breast cancer (stages 1 or 2).¹ Standard treatment for early-stage breast cancer includes mastectomy or breast-conserving surgery, radiation therapy following breast conservation, and adjuvant systemic therapy for all node-positive and many node-negative women.² For health care providers, coordinating the care of these patients is a significant challenge. First, early-stage breast cancer is a complex condition that often requires several physicians to work in a coordinated fashion to deliver the most effective treatments available. Indeed, physicians of different specialties often provide local surgical and radiation treatment, systemic chemotherapy, and hormonal therapies. Second, much of the therapy women receive for this condition is delivered in outpatient settings. Although providing such care in outpatient settings can conserve resources and enhance patient comfort, it can also fragment care by requiring additional efforts by providers to coordinate and keep track of care performed by other providers.

The challenges inherent in coordinating care for women with early-stage breast cancer may contribute to the underuse of effective therapies. Research consistently shows substantial underuse of adjuvant local and systemic therapies for women with early-stage breast cancer³⁻¹² despite numerous randomized trials and large meta-analyses demonstrating a positive effect of these therapies on clinical outcomes.^{12,13} Delivery of breast cancer care ranges from centralized Breast Centers with multispecialty consultation in one place at one time to a fully decentralized model with specialists in different cities and different organizations. We believe that for complex conditions requiring multiple interventions performed by different providers, the presence of coordination mechanisms can affect the provision and quality of multidisciplinary care. Studies have shown that better coordination of inpatient care is associated with lower inpatient morbidity and mortality and higher patient satisfaction,¹⁴⁻¹⁶ and better coordination of outpatient care is associated with higher levels of perceived health status and receipt of preventive services.^{17,18} However, these studies do not describe the specific mechanisms used to coordinate care.

We conducted an exploratory study of the specific coordination approaches used by breast cancer providers to help early-stage breast cancer patients access and receive care. To conduct this study, we developed a conceptual framework that posited 6 dimensions of coordination for early-stage breast cancer: standardization of work, feedback mechanisms, patient support, monitoring the quality of care, information systems, and location of care sites (See Fig. 1). Each dimension comprises different specific mechanisms. The central hypothesis underlying Figure 1 is that for complex conditions requiring multiple interventions performed by different providers, the presence of coordination mechanisms can affect the quality

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FIGURE 1. Conceptual model: coordination of care for complex conditions.

of patient care, resulting in the provision of the full complement of effective multidisciplinary care. Our conceptual framework is grounded in organizational theory. Organizational theory categorizes coordination into 2 major types: programming and feedback.¹⁹ Programming is a way of standardizing work performance; standardization refers to efforts to anticipate work requirements in advance and develop programmed approaches for addressing those requirements. It specifies and routinizes the processes of work to be performed and includes the use of rules, procedures, and protocols. Standardization is most appropriately used for routine work activities that require little personal interaction.^{20,21} In the case of breast cancer, examples include practice guidelines, care maps, physician reminders, and tickler systems to initiate scheduling of follow-up appointments.

Feedback mechanisms refer to personal approaches that facilitate communication among staff. Examples of this include supervision in which information is exchanged between people, one of whom is responsible for the other's work, "mutual adjustment," in which information about work performance is exchanged between people who are not in a hierarchical relationship, and group coordination in which information is exchanged among several individuals. Regularly scheduled multidisciplinary meetings to discuss patient care issues are considered feedback mechanisms because they provide physicians with an opportunity to exchange information about patient care issues.

Patient support is a different type of personal approach dimension, which facilitates information exchange between staff and patients. An example is the assignment of an individual to help navigate a patient through the multiple steps of care.²²

Monitoring quality of care is considered to be a coordination dimension because of the importance of a site's ability to monitor its practice and implement programs to improve care. An example of this dimension is the identification of quality improvement projects that incorporate issues

identified by patient educators or those that utilize tumor registry data to profile individual physician performance.

Information systems may inform clinical decision making in a timely and convenient way by making pathology or radiology findings readily available at computer terminals in the hospital or in off-site physician offices. Such systems may also support standardization of care by triggering prompts for abnormal lab results or appointments that need to be scheduled.

Physical location is included as a coordination dimension because the physical proximity of clinical services may facilitate frequent informal consultations among physicians about shared patients and make it easier for women to access the different kinds of care needed. An example is the Breast Center, a single site that provides multidisciplinary "one-stop shopping" care for breast cancer patients.

METHODS

Six hospitals participated in the study: 1 urban tertiary academic medical center (1,171 beds), 2 urban community teaching hospitals (493 and 705 beds, respectively), 1 suburban community teaching hospital (520 beds), 1 urban municipal teaching hospital (450 beds), and 1 rural community cancer center (442 beds). One of the hospitals, Hospital II, has a Diagnostic Breast Center. Hospitals I-IV had participated in a quality improvement project for which treatment data were collected from 280 physician offices, inpatient records, and billing databases. Details of the methodology have been previously published.^{3,23} Hospitals V and VI were included because they have innovative breast cancer programs. At Hospital V, the tumor registrar provided data abstracts for all their stage 1 and 2 breast cancer patients between 1995 and 1996, the same study years and eligibility criteria of the aforementioned quality improvement study. Performance data were not available for Hospital VI.

To assess the approaches used to coordinate care, we interviewed individuals representing all the disciplines that

Table 1. Distribution of Interviewees

Surgeons	16
Medical oncologists	8
Radiation oncologists	6
Radiologists	3
Senior clinical directors*	4
Primary care physicians	2
Nurses†	9
Patient educators/navigators/case coordinators	9
Administrative personnel‡	10
Total	67

* Department chiefs, medical directors, directors of quality, program managers.

† Seven nurses had direct clinical responsibilities; 2 were managers.

‡ Individuals responsible for scheduling patient appointments, tracking consult and laboratory results: schedulers, secretaries, clerks, tumor registrars, quality assurance personnel.

were involved in providing care to women with early-stage breast cancer. At each hospital, a senior clinical or administrative individual involved in breast cancer care provided a list of clinicians, both full-time salaried and voluntary physicians, who care for women with early-stage breast cancer including: surgeons with high and low volumes of breast cancer cases; radiation and medical oncologists; radiologists; pathologists; internists, their office managers, nurses and clerical staff; and senior clinical and senior quality personnel. All of the identified clinicians and their staff agreed to participate. We interviewed 67 individuals in the hospital and in their office practices across all 6 sites (see Table 1). One-hour semistructured interviews were designed to elicit descriptions of the types of coordination mechanisms used and their perceived value. We used semistructured interviews because this research strategy is appropriate when a "how" or "why" question is being asked.²⁴ All interviewees were asked to describe their usual approach to providing care for a woman with a detected breast cancer through completion of cancer treatment and subsequent cancer monitoring. We asked open-ended questions about approaches used in their office practices and in the hospital to coordinate care for their breast cancer patients. We also asked open-ended questions about each of the domains that constitute our conceptual framework for coordination. Each interview was audiotaped and was also documented through the detailed notes of a research assistant and was approximately 1 hour long. We analyzed the content of each interview, as recorded in both the tapes and notes, by identifying mechanisms of coordination, coding and tabulating responses. We also toured each of the physical locales and attended multidisciplinary meetings at 2 of the hospitals.

RESULTS

We observed 7 different coordination mechanisms of varying perceived value including: tracking of referrals, use of protocols, regularly-scheduled multidisciplinary

meetings, feedback of performance data, patient support, computerized systems, and a single physical location. None of the sites has done much to standardize processes for tracking and following up on breast cancer care or on patients who do not keep appointments, tasks that ostensibly are amenable to such approaches. All of the physicians we interviewed use follow-up visits as a way to check their patients' receipt of recommended care provided by other physicians. Despite physicians' reliance on follow-up visits to ensure the receipt of care, less than half have a mechanism to follow up patients who do not keep their appointments by either calling patients directly or designating a staff person to call. One site does have a designated individual to schedule all follow-up appointments and tests, and reschedule missed appointments. None of the sites has a mechanism to remind physicians to check receipt of adjuvant care provided by other physicians when patients do return for follow-up appointments.

None of the physicians has a standardized process to track results of referrals or receipt of treatment provided by other physicians; 4 use written lists to remind them to check a patient's consult or laboratory results and 6 said that they make a "mental note." Many of the physicians commented on the difficulties of keeping track of patients and thought that a computerized system could help.

Only 1 of the participating sites has guidelines or protocols in place for standardizing the diagnosis and treatment processes. Here, physicians routinely refer to the National Comprehensive Cancer Network's (NCCN) guidelines during their weekly cancer meetings and most feel inclusion of the guidelines contributes positively to the medical discussions.

The feedback mechanisms most commonly used were multidisciplinary cancer meetings with either a patient management or an educational focus. At the 2 sites with "patient management"—focused discussions complemented by educational discussions, attendance is reported to be excellent. Many of the physicians expressed the importance of having a weekly regularly scheduled opportunity to meet and talk with colleagues with whom they share care of many patients. All 6 hospitals have a multidisciplinary tumor board meeting. In contrast to the management-focused meetings, these have a strong educational rather than patient management focus; attendance is reported to be highly variable as is the perceived value. None of the participating sites has a process for the routine review and feedback of individual physician practice.

Three of the participating sites have patient support programs to coordinate care. Although the programs vary substantially, they all include some elements of the following: a systematic method to identify patients; education about breast cancer including treatment options and counseling; calls to patients to remind them of upcoming appointments; and navigators to bring patients to appointments or enable them to attend appointments, for example, by arranging for child care or transportation.²² Two of the 3 programs are staffed with trained volunteers. Physicians

Table 2. Presence of Coordination Mechanisms by Level of Hospital Performance

	Hospitals					
	I	II	III	IV	V	VI*
Rates of performance						
Radiation following breast conservation, %	79	82	69	87	90	—
Systemic treatment for tumors size 1 cm+, %	74	71	75	86	83	—
Valued mechanisms present†						
Tracking of referrals	—	—	—	—	—	—
Patient support	—	—	—	+	+	+
Regularly scheduled multidisciplinary breast cancer meetings	—	+	—	+	—	—
Feedback of data	—	—	—	—	+	—
Use of guidelines or protocols	—	—	—	—	+	—
Computerized systems	—	—	—	+	+	—
Same physical location‡	—	—	—	—	—	—
Total of different valued mechanisms, N	0	1	0	3	4	1

* Rates of performance unavailable for Hospital VI.

† Mechanism perceived as valuable by at least 1 individual.

‡ Same location of all offices for diagnostics and treatments: radiology, pathology, surgery, medical, and radiation oncology.

Hospital size/number of beds: I = 493, II = 520, III = 705, IV = 1,171, V = 442, VI = 450; (+), mechanism present; (—), mechanism absent.

found these programs extremely valuable because they provide services that were otherwise missing at the sites or supplement services, thereby reducing physicians' workload. For example, because physicians had difficulties getting test results at Hospitals IV and VI, the navigators tracked down and brought the results to the physicians. At Hospitals IV and V, patient support programs educate and counsel patients about cancer and cancer treatments, and several physicians felt that these improved patient understanding and eased physicians' efforts in explaining treatment options.

There was little monitoring of the quality of breast cancer care. Few interviewees were familiar with any type of breast cancer quality assurance or improvement activities at their hospital. At 1 hospital, however, tumor registry data are reviewed to determine whether the cancer diagnosis and treatment are in accordance with the NCCN guidelines. This hospital also incorporates issues identified by the patient educators into the hospital's Cancer Committee quality improvement projects.

Existing information systems are not routinely used to obtain clinical data, trigger follow-up visits, or prompt physicians to check on receipt of therapy during follow-up visits. None of the physicians with offices outside the hospital are able to access computerized hospital clinical data at their offices. At 4 of the 6 sites, some test results are available on computer terminals throughout the hospital, but few physicians could access the data because terminals were not available in the hospital-based offices where they see patients.

Physical distance did not appear to play a significant role in facilitating or impeding coordination of care. While some physicians feel that close proximity facilitates contact between specialists, telephone and fax have bridged the distance between specialists. In fact, specialists located in the same building, even the same floor, communicate by

telephone and fax. Weekly meetings that provide the opportunity for informal discussion are felt to be important in overcoming physical distances.

As an additional analysis for this exploratory investigation, we examined the relationship between a site's patterns of coordination as discussed above and its performance in providing appropriate care to women with early-stage breast cancer. Performance was measured in 2 ways: 1) a site's percentage of early-stage breast cancer patients with breast-conserving surgery who received radiotherapy, and 2) a site's percentage of early-stage breast cancer patients with tumors larger than 1 cm who received systemic chemotherapy or hormonal therapy. Performance data are available for 5 of the 6 sites. Table 2 presents the performance data and the presence of coordination mechanisms. It appears that there are a greater number of coordination mechanisms in place in Hospitals IV and V, the 2 hospitals with higher rates of receipt of effective adjuvant therapies. At these high-coordination hospitals, on average, 88% of women received radiotherapy and 84% of women received systemic therapy, compared with 76% and 73%, respectively, at the other lower-coordination hospitals, Hospitals I, II, and III (χ^2 ; $P = .001$ and $P < .0005$, respectively).

DISCUSSION

Study sites use a variety of mechanisms to coordinate care for women with early-stage breast cancer, but they lack standardized approaches to coordination. No site has a systematic approach to track receipt of adjuvant care provided by other specialists. Some but not all physician offices have a mechanism in place to ensure scheduling of follow-up appointments or recall of patients who do not keep their appointments. Although information systems can be an important resource for standardizing care, physicians report that their available information systems

do not help facilitate timely receipt of information that affects their delivery of care. Physicians report that regularly scheduled, weekly multidisciplinary meetings are helpful, particularly when they provide a direct patient management focus or the opportunity to meet and informally exchange information about mutual patients or discuss diagnostic and treatment dilemmas. Patient support mechanisms are also reported by interviewees to be extremely valuable because they provide both patients and physicians with services that are otherwise lacking.

Previous research suggests that the way care is coordinated in inpatient settings affects outcomes such as patient mortality and morbidity.^{14,15,25,26} Little information exists, however, about how to coordinate care in the outpatient setting. Common conditions that require treatment by multiple different disciplines in a fragmented outpatient setting could benefit from a framework to help coordinate care. Case management, one approach to coordinating care, has theoretical benefits, but a review of randomized trials of primary care strategies found few programs that had an impact on health care resource use and patient functional status.²⁷ One successful diabetes case management intervention combined different coordination mechanisms: trained educators, explicit guidelines and regular communication with clinical experts, collection and organization of relevant data, and reminders and feedback.²⁸ The approaches used in this intervention exemplify patient support, personal feedback, and standardization of work, the same mechanisms valued by the breast cancer providers we interviewed.²⁹ Identifying the specific mechanisms that result in the greatest change in physician or patient behavior could offer the medical community a framework for customizing and prioritizing interventions. For example, coordination mechanisms that could be standardized and systematically incorporated into routine work might result in changes that could reap benefits beyond the initial investment period.

The majority of coordination mechanisms such as multidisciplinary meetings, patient support programs, information systems, and for most hospital-based salaried physicians, scheduling and follow-up are under the hospital's aegis. Having the majority of coordination mechanisms under the auspices of the hospital provides these institutions with the opportunity to implement new systems or modify existing systems to improve the coordination of outpatient breast cancer care.

This study was designed to explore and describe a range of different approaches used to coordinate care for early-stage breast cancer, not to definitively determine the prevalence of these approaches or their exact impact on receipt of care. To provide the breadth of approaches currently used, we chose hospitals with a range of volume of breast cancer cases, hospitals with innovative programs implemented to provide high-quality breast cancer care, and a mix of municipal, community and tertiary referral hospitals. Although the treatment data were collected for other purposes 2 years prior to this project, the types of

coordination mechanisms used at each of the sites during this time interval did not undergo notable change. We identified physicians, providers, and administrative staff from hospital-based individuals. While we sought a broad range of individuals, it is possible that the experiences of the interviewees recommended may not reflect the complete range of approaches used to coordinate care. We interviewed physicians both in the hospital and in their offices and asked them about both hospital-based and office-based approaches they use to coordinate care. However, given the limited scope of this study, we may not have identified the full range of approaches available and used in a variety of practice types. Our findings are based on interviews and not quantitative assessments of the existence and use of specific coordination approaches. It is possible that the hospitals' locations, in and around New York State, may limit the generalizability of the findings.

Our description of the valued coordination mechanisms may help inform interventions that the medical community will need to mount as it responds to mandates for increasing accountability with little guidance as to how to best fulfill the requirements.^{30,31} This is particularly relevant for complex conditions treated by multiple providers in outpatient settings. Two valued mechanisms include regularly scheduled meetings with a patient management focus, and the systematic use of patient support programs such as educators and navigators. A coordination mechanism striking in its absence and perceived to be needed is a systematic tracking of the receipt of care or the results of referrals. Our data suggest that greater coordination may be associated with increased provision of effective care. Since the majority of valued mechanisms are under the hospital's purview, hospital leadership should consider implementing mechanisms to coordinate care. Future work should link specific coordination mechanisms and processes of work with critical processes of care and determine which mechanisms are the most effective at improving the quality of breast cancer care.

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