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Understanding the Challenges of Adjuvant Treatment Measurement and Reporting in Breast Cancer:

Cancer Treatment Measuring and Reporting

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Abstract

Background—Healthcare accrediting organizations and insurers increasingly require reporting of clinical data, and cancer treatment is one area of enhanced scrutiny.

Objectives—To compare rates of received versus reported adjuvant breast cancer treatments, and to assess barriers to measuring and reporting treatments to the tumor registry (TR) of a high-volume medical center with both hospital-based and community-based oncologists.

Research Design—We calculated rates of received treatments using data collected using chart abstraction (N = 115) and compared these with rates of reported treatments from the TR (N = 535). We conducted 31 indepth interviews with clinical and administrative informants. Asking about perceptions of the TR, current reporting methods, and reporting barriers. Interviews were recorded, transcribed, and analyzed using deductive and inductive methods.

Results—Rates of reported versus received treatments were radiation therapy after breast-conserving surgery 22% versus 84% ($P < 0.0001$); chemotherapy for stage 2 or 3: 17% versus 79% ($P < 0.0001$); hormonal therapy for stage 2 or 3: 1% versus 91% ($P < 0.0001$). Comparing community-based versus hospital-based oncologists' rates reported to the TR, we found the following differences: radiation therapy post-breast conserving surgery 12% versus 32% (< 0.0001); chemotherapy 8% versus 29% (< 0.0001); and hormonal therapy 0% versus 3% (0.09).We found 4 key barriers to measuring and reporting poor understanding about the TR, limited information technology capabilities, poor communication, and mistrust.

Conclusions—Efforts to improve cancer care quality by improved treatment reporting must overcome key barriers, especially those involving information exchange and mistrust. Communications between the TR and oncology practices must improve to facilitate better treatment measurement and reporting.

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Keywords

breast cancer; adjuvant therapy; measurement; reporting; communications; quality improvement

In 2007, the American College of Surgeons' Commission on Cancer, in conjunction with the National Quality Forum, took the bold step of adding measures of adjuvant breast and colon cancer treatments to their accreditation process. The step was bold as it made hospital tumor registrars accountable for reporting care often delivered beyond hospital walls and jurisdictions, and created a particular challenge for hospitals that had significant proportions of community-based physicians providing adjuvant treatments. Although reporting rates of treatment is not yet required, these adjuvant treatment measures will likely serve as a basis for the quality of care ratings, and possibly for reimbursement as pay-for-performance incentive systems extend to include new metrics.[1,2] Moreover, given that measurement and reporting are the cornerstones of quality improvement efforts,[3] it is imperative that these treatment measurement and reporting processes be both timely and accurate.

Adjuvant cancer treatments are often given by different out-of-hospital physicians and few practices, whether hospital based or community based, are able to automatically identify and report treatments. As a result, problems with the accuracy and underreporting of treatments provided in the outpatient setting have been acknowledged and studied.[4–6] In practice, the accuracy of treatment reporting has been found to vary with the level of decentralization of care delivery. A study demonstrated better reporting of radiation therapy that was delivered through limited numbers of licensed facilities (as per statistical data from the National Cancer Institute's Surveillance, Epidemiology and End Results program, 80% to 95%) compared with chemotherapy reporting that was more often delivered in oncologists' individual offices (Surveillance, Epidemiology and End Results reports 60% complete chemotherapy data)[7]; the least accurate reporting was for hormonal therapies that can be written by any physician (36% accuracy).[4]

Measuring and reporting accurate adjuvant treatment data pose significant challenges to hospital tumor registries as they must obtain data from numerous sites both within the hospital (intraorganizational practice sites) and outside the hospital (interorganizational practice sites with varying affiliations and structures). Hospitals may have varying levels of jurisdiction over independent office practices, thus creating difficulties when trying to ensure comprehensive data reporting from these physicians' practices. Furthermore, the ability to report adjuvant treatments requires the ability to find that information. Despite the explosive growth in electronic medical record (EMR) systems, only about one quarter of U.S. physician practices use EMRs,[8] and only 20% report receiving feedback about clinical performance from their EMR systems.[9] In addition, physicians are often concerned about releasing data in the age of the Health Information Portability and Accountability Act.[10] These significant challenges thus hinder hospitals' abilities to obtain, compile, and report adjuvant treatment data.

We initiated this study to assess the scope of the problem of physicians' reporting of adjuvant treatments to a hospital tumor registry (TR), and to improve our understanding of treatment measurement and reporting barriers to inform future efforts aimed to improve breast cancer treatment measurement and reporting.

METHODS

Study Setting

Our study was conducted at a high breast cancer volume hospital that is both nestled between and serves the poorest and wealthiest communities in a large urban area. At the time of our study, the hospital was striving to achieve the necessary standards for American College of Surgeons' Commission on Cancer accreditation. The single hospital locale includes large numbers of community-based and hospital-based oncologists, with 17 medical and 2 radiation oncologists who treat breast cancer. Of these physicians, 83% were community-based in solo and group practices, and 17% were hospital based in faculty practices and resident clinics. All providers and practice sites were located within the same large, metropolitan area. The hospital had an EMR, albeit not an integrated one. The tumor registrar had access to the radiation oncology electronic record and received regular feeds of data from the pharmacy EMR and from the oncology clinics.

This study was composed of 2 parts: a quantitative assessment of treatment reporting to the TR and a qualitative assessment of factors affecting treatment measurement and reporting.

Quantitative Assessment

In the quantitative component of our study, we compared treatments received with treatments reported to the hospital TR during the same time period. The data providing evidence of adjuvant treatments received were collected as part of a National Cancer Institute (NCI)-funded study in which recruited women had a new, primary, early-stage breast cancer, were treated at the study hospital between October 2006 and September 2009 and consented to a trial-testing community-based patient assistance. Surgical, medical, and radiation treatment information was collected tthrough chart abstraction starting with review of charts in the surgeons' offices and review of hospital-based records, and then involved tracking data further to oncologists' office records. We identified treating oncologists through records in the surgeons' offices, or via clues in the medical record (eg name of physician ordering chemotherapy, hormonal or radiation treatments, referring physicians). If we were unable to identify the oncologists, we contacted patients to obtain their physicians' names and contact information.

For comparison of data of treatments reported, we obtained adjuvant treatment data from the TR for stage 2 or 3 analytic cases undergoing surgery at the study hospital for the 2007 to 2009 time period. We limited our NCI study and TR populations to stage 2 or 3 disease to maximize the likelihood that the patients in this population would be appropriately treated with adjuvant therapy.

Across the 2 groups we classified hospital-based versus community-based physician practices on the basis of practice location. We then verified this classification after consultation with a physician leader at the study hospital who was familiar with both full-time and community-based voluntary physicians affiliated with the hospital.

We compared the rates of treatments received versus treatments reported using *t*-tests, and performed χ^2 analyses to compare treatment rates between community-based and hospital-based physicians.

Qualitative Assessment

In our qualitative assessment,[11] we used multiple key informant interviews to examine both organizations' and physicians' perspectives about treatment measurement and reporting for breast cancer patients associated with the study hospital. We conformed to the standards of rigorous qualitative research,[12–14] paying special attention to in-depth interview[15] techniques to conduct our study.

We identified target informants based on their roles in providing or supporting the provision of breast cancer adjuvant treatments associated with patients who were surgically treated at the study hospital. Hospital-based target informants included oncologists, administrators, and clinical and information technology (IT) leaders of breast cancer care at the study hospital, and also the hospital tumor registrar. Community-based target informants included physicians at each of the community-based practices and their office staff responsible for communicating with the hospital and with patients. Two key informants (6%) contacted declined to participate.

We created semistructured interview guides tailored to key informant type (ie, physician, leadership, administrative staff, and tumor registrar) to guide the interview process and standardize probing by interview domain. We present the list of 4 general interview domains and sample topics covered in each domain in Table 1.

Interviews lasted an average of 50 minutes (range, 30–90 min) and were conducted in person. One investigator led each interview (N.A.B.), and a cointerviewer (A.S.M., J.W.) was present to assist. All interviews were recorded, transcribed, and then verified and corrected by a study investigator. The Institutional Review Board of the study hospital approved this study.

Analyses applied a combination of inductive and deductive methods using a grounded theory approach.[16,17] Throughout the study, members of the interview team read and discussed interview transcripts and preliminary findings. Our iterative analytic process enabled us to explore themes as they emerged in the data, and permitted us to verify emergent themes as our study progressed and we held additional key informant interviews.

After we had completed all of the interviews, we developed a coding team that was composed of the lead qualitative investigator (A.S.M.) and a research assistant (R.F.). Throughout the coding process, coders held regular discussions to ensure consistency of coding and agreement about our identification of major themes around barriers to treatment measurement and reporting. We used the Atlas.ti (version 6.0) software program to facilitate the coding and analysis process.[18]

RESULTS

Quantitative Assessment

Of the 115 women with a stage 2 or 3 breast cancer who participated in the NCI study, 60% were treated by community-based and 40% by hospital-based oncologists. In contrast, of the 535 stage 2 or 3 breast cancer patients in the TR, 52% were treated by community-based and 48% by hospital-based oncologists. Treatment rates reported to the TR as compared with treatments received as documented in the medical records were significantly different: radiation therapy after breast-conserving surgery 22% versus 84% ($P < 0.0001$), chemotherapy 17% versus 79% ($P < 0.0001$), and hormonal therapy 1% versus 91% ($P < 0.0001$).

We found notable differences between community-based and hospital-based oncologists' rates of treatments reported compared with received by type of practice setting (Table 2). Rates reported from community-based oncologists were strikingly lower than from hospital-based oncologists. There was no difference in rates of treatments received between hospital-based and community-based physicians.

Qualitative Assessment

Study Population—We interviewed 31 organizational and clinical informants across the hospital and community sites (Table 3). Key informants included community-based and hospital-based surgical and radiation oncologists, organizational leaders, office staff, and the hospital tumor registrar.

Barriers to Tracking and Feedback—Across our key informant interviews, 4 main types of barriers emerged around measurement and reporting of adjuvant therapies: (1) poor understanding about the TR; (2) limited information technologies; (3) communication problems; and (4) mistrust.

Poor Understanding about the Tumor Registry: A majority of respondents from both hospital-based and community-based practices had a poor understanding about the role of the TR, thus creating an important measurement and reporting barrier. Several hospital-based physicians were largely unaware about the registry and its goals. One commented that “I didn’t even know that we had a tumor registry.” Another asked the study investigators, “How long have we had the tumor registry? For years?” Although community-based physicians tended to be more aware of the existence of the registry, they were often confused about what they were supposed to do with respect to reporting. As one reflected,

> “*The question is, am I supposed to be reporting all my patients to some entity? As far as I know, I am not supposed to be. It is not HIV. As far as I know, it is not a communicable disease that puts the community at risk. So, what you are telling me is frankly surprising. Because I am a pretty responsible person. So, if I was supposed to be reporting to someone, no one has told me.*”

Physicians who were aware of the registry were still confused about its role, its value, and its potential. As a hospital-based physician explained, “…who do they want to get in our cancer registry? …Do they want every patient diagnosed with cancer? Then why am I only getting notices for a couple of patients who were diagnosed when I was on service that I don’t even follow-up with?” Another physician summarized, “The perception I think many people have of the tumor registry is that its useless.”

Limited ITs: When discussing approaches to measurement and reporting, most physicians described how they tracked patients in the absence of supporting IT or electronic records, and many commented about how the lack of integrated IT created a barrier. One community-based physician explained, “Well, we have paper records. They are very cumbersome, and the filing is a nightmare.” When then asked about whether they had a way to easily determine what treatments a patient had, physicians explained how the process was never easy. As one commented, even though he could find “all my patients that have carcinoma of the breast” on his computer, there was no way to determine what treatments the patients had received: “No, I would have to access their charts.”

As a result of this barrier, physicians had learned to make due given the technologies they did or did not have in their practices. One hospital-based physician noted, “If I order a test, I make a note in my Blackberry to follow it up.” A voluntary physician explained, “I know the patients. They come in and I know when they are supposed to have X, Y, Z.”

Communication Problems with the Registry: There was a striking communication disconnect between physicians and the tumor registrar’s office. Both community-based and hospital-based physicians reported that they never received requests from the TR to stage patients or provide any other information. One community-based physician noted, “I haven’t been asked to report anything other than sending reports to referring doctors, which I feel I am obligated to do since they send me the patient, to keep them up to date."

Yet, from the perspective of the tumor registrar, communications from the TR office were regular and clear. The registrar explained, "We will send information to the physicians' offices both internally and externally. Some [physicians] will be good, some will be very good at responding…but outpatient is horrible." Particularly frustrating, she reported, was when requests had to be repeated and repeated: "We fax. We refax. They insist they didn't receive it. We fax again. It's ridiculous." Further, when the study investigators shared the general sense from physician respondents that the TR did not send any requests or that they did not see any requests that were sent, the registrar responded, "Well if they don't, then they probably need to talk with their assistants." Our interviews with office staff, however, did not support the TR office's contention that their communications were clear or well understood.

Even processes that were established to facilitate reporting were often poorly communicated. One community-based physician described how he happened to discover the electronic reporting program that enabled him to provide information to the TR [e-Outcomes] when he was cleaning out his email spam filter:

> "*e-Outcomes snuck up on me. I come home one day and I look through my spam filter. It said e-outcomes, okay. It looks kind of official…. So I clicked on it and it turns out, yeah, this thing is pretty legit.… That is how I stumbled on it and I said, 'Wow! This is the real thing!' And then I realized they had been trying to reach me for awhile. …Because the thing is dated from a year earlier….* "

Mistrust Between Physicians and the Hospital: Mistrust of the hospital emerged as an important barrier that provided insight into the contrasting perspectives of community-based and hospital-based physicians affiliated with the hospital organization. We identified 2 subthemes associated with the issue of reporting: (1) mistrust about losing patients and (2) mistrust about data and privacy.

Community physicians expressed considerable skepticism about whether the hospital was looking out for their best interests regarding losing patients to hospital-based physicians. The mistrust theme emerged in their comments about how the reporting process was somehow one sided, and hinted that by providing more information to the hospital, it might somehow make it easier for the hospital to "steal" their patients. As one explained, "When I refer a patient to one of the full-time oncologists for whatever, I almost never get reports back and the patient disappears. I tell them, 'Why should I send patients to XXX? If I send a patient to another institution for a bone marrow transplant, at least I get the patient back after it's done.'"

The second mistrust subtheme involved community physicians' mistrust about data and data privacy. One community-based physician explained, "I'm very suspicious of what's being done with the information that I send any place. Stuff that I don't send, it's there." Another noted,

> "*Data can be abused. Once you start sharing data, you might even start off in a way where there was no real intent. But then, depending upon where that data resides, a year from now you could have somebody who's doing some research and say, 'Oh, I've got this data.' And now suddenly somebody is doing an analysis which is totally different than the original intention.*"

From the hospital's perspective, comments did not clearly indicate any intent to abuse data intended for the registry, but informants did describe how reported data might be shared publicly for quality improvement purposes. A member of medical leadership speculated about the ability to encourage better quality of care by publishing data, commenting, “if you publish them, will people feel ashamed to do better, to improve?” The contrasting views of community physicians’ and hospital administrations’ with respect to data and information exchange thus contributed to these physicians’ mistrust of the hospital itself.

DISCUSSION

Significance

Our study suggests that the reporting of treatment data from hospital-based and especially from community-based physicians is problematic, and that the barriers to treatment reporting are not simply structural. Instead, issues such as communication and trust complicate the treatment measurement and reporting process. Nonetheless, accurate measurement and reporting of performance is the critical first step of any quality improvement activity,[3] and both are mandatory for American College of Surgeons’ Commission on Cancer accreditation.

Improving the quality of breast cancer treatment reporting is challenging because much of adjuvant cancer care is delivered in individual, community-based physician office practices, by multiple different providers. Even though hospitals may increasingly be held accountable for the care provided in out-of-hospital physician office practices, they have variable oversight capacity and little ability to change individual physician practices. We found substantial differences in rates of reported versus received adjuvant treatments, documenting this reporting problem, and learned about important barriers to reporting that will have to be addressed. These differences are certainly troubling in the context of breast cancer adjuvant therapy treatments, but also suggest that relying solely on reported rates of treatment to confirm the quality of care provided may be problematic. Furthermore, given increasing reliance on reported treatments to calculate performance metrics and even determine incentive payments (eg, pay for performance (P4P) incentive systems), our finding about inaccurate reporting may be of particular concern.

Moving forward, the opportunity for hospitals striving to improve measurement and reporting of adjuvant breast cancer treatments appears 2-fold: (1) educate and engage clinicians and their staff to ensure complete and accurate reporting, and (2) enable both in-hospital and community-based physician practices to increase reporting. Part of the solution clearly lies with improved IT availability and ongoing technologic support. For instance, enhanced IT systems that enable automated reporting and/or integration of different electronic health record systems can help improve the reliability of reporting as well as facilitate better communications both among providers and institutions. However, although technology solutions can facilitate case identification and measurement, they do not guarantee reporting success. More challenging, perhaps, will be the need to engage clinicians in this process as this will likely require addressing underlying cultural beliefs, as well as deep-seated values and issues associated with power in interorganizational relationships, for example,[19,20] that all may contribute to the perceived reporting barriers we found.

Limitations

Our study is limited in that we focused on a single urban hospital, making it potentially difficult to generalize our findings to other settings. However, this single site has a high volume of breast cancer cases served through both hospital-based and community-based practices, and patients included a combination of well-insured and Medicaid patients, thus providing variability across providers and patients similar to what is found in most U.S.

healthcare settings. In addition, our study's practice setting offered us the opportunity to explore issues of information transfer from intraorganizational hospital-based office practices and interorganizational community-based practices, offering insight that could ostensibly be translated to other similarly diverse practice settings.

Furthermore, although our results provide evidence about the complexity of the treatment reporting process, we have no evidence that the solutions we discuss such as education, awareness, and enhanced IT will solve the reporting problem. We did find persistence across the themes and subthemes we report across respondent groups, thus indicating that these barriers might be salient in other settings and applicable to other conditions involving multidisciplinary care delivered in different organizational settings. However, our study was not designed to study the impact of these solutions. Instead, the insight we provide about barriers to treatment measurement and reporting can be used to help raise awareness about both these challenges and potential solutions in the context of a difficult problem affecting the quality of cancer care delivered in practice.

Future research will benefit from similar mixed methods approaches, combining quantitative and qualitative data to explore the complex issues associated with delivering breast cancer adjuvant therapies in different practice settings. Studies designed to implement and evaluate interventions to improve treatment measurement and reporting in similarly complex hospital and community-based settings would be particularly informative and help improve our ability to increase the quality of care provided to cancer patients across settings.

CONCLUSIONS

The ability of hospital tumor registries to systematically and accurately capture and report cancer adjuvant treatments provided in busy outpatient practices is challenged by the limitations of information systems, organizational barriers, and communications both within and outside the hospital. Yet, these treatment data can enable registrars to give real-time feedback about needed therapies and interventions and thus, improve the quality of cancer care delivered. Given increasing attention to performance metrics and public accountability for cancer care delivered within and beyond institutional walls, both hospital administration and oncology practices should address underlying issues that affect trust and their abilities to measure and report cancer treatment, paying particular attention to opportunities to improve communication both within and across settings.

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TABLE 1

Interview Domains and Sample Interview Questions

- **I.** Introduction and background
  - To start, could you please tell me about your role in the organization and how long you been in this role? (Are there other positions you have held in this or other organizations?)
- **II.** Organizational change and change processes
  - Can you tell me any stories about how you've been involved in formal organizational change programs within [hospital]? (Probe: For example, implementation of a new IT system or initiation of a new hospital-wide program for patient safety)
  - What went well with this organizational change? (Probe: For example planning processes, use of incentives, organizational support, use of teams, ability so solve problems that arose) (*facilitators of change)*
  - What challenges did you experience participating in this organizational change? (What didn't go so well?) (*barriers to change*)
- **III.** Cancer treatment measuring and reporting
  - Could you describe how a cancer patient goes through the diagnosis, treatment, and follow-up process at [this hospital]?
  - What do you believe are the major barriers to timely and accurate treatment measurement and reporting?
- **IV.** Moving forward with this research
  - Competing priorities
    - Are there other changes underway within the tumor registry or within Cancer Care that may affect practices' ability to increase their measurement and reporting of cancer treatments?
  - Resource support
    - What kinds of resources does the medical center have to support and sustain improved treatment reporting to the tumor registry?
  - Critical success factors and readiness for change
    - What do you think will be 3–5 key things this hospital needs to keep in mind to make sure the accreditation effort succeeds? (*critical success factors*).
  - Final recommendations and advice
    - Do you have any further suggestions to help us with this project?

TABLE 2

Rates of Adjuvant Treatment Reported to the Tumor Registry and Collected for a NCI Research Study

	Treatments Reported (Tumor Registry Data)				**Treatments Received (Research Study Data)**			
	N	**Community-based Oncologists**	**Hospital-based Oncologists**	***P***	**N**	**Community-based Oncologists**	**Hospital-based Oncologists**	***P***
RT post-BCS	383	24/199 (12%)	55/173 (32%)	<0.0001	75	33/37 (89%)	28/38 (74%)	0.15
Chemo for stage 2+	291	13/158 (8%)	36/126 (29%)	<0.0001	53	24/27 (89%)	17/26 (65%)	0.07
HT for ER+ stage 2+	205	0/108 (0%)	3/93 (3%)	0.09	44	20/23 (87%)	19/21 (90%)	0.87

BCS indicates breast-conserving surgery; Chemo, chemotherapy; ER+, estrogen receptor positive; HT, hormonal therapy; RT, radiotherapy.

TABLE 3

Key Informants, by Type (n = 31)

Key Informant Type	**N (%)**
Hospital-based informants (n = 22)	
Physicians (full-time)	5 (16%)
Office staff (full-time)	4 (13%)
Hospital leadership-physicians	6 (19%)
Hospital leadership-administrators	4 (13%)
Information technology managers	2 (6%)
Hospital tumor registrar	1 (3%)
Community-based informants (n = 9)	
Physicians (voluntary)	4 (13%)
Office staff (voluntary)	5 (16%)
Total	31