How to Improve Breast Cancer Care
Measurement and Reporting: Suggestions from a Complex Urban Hospital

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Improving Breast Cancer Care Measurement and Reporting in a Complex, Urban Hospital Setting

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Executive Summary

Increasing scrutiny of clinical data reporting by healthcare accrediting organizations is challenging hospitals to improve measurement and reporting, especially in the area of cancer care. We sought to explore barriers to breast cancer adjuvant treatment measurement and reporting to a hospital tumor registry (TR), and identify opportunities to improve these processes.

We conducted 31 key informant interviews with administrators and clinicians associated with a large urban hospital that treats a high volume of breast cancer patients. In this setting, up to 40% of early-stage breast cancer cases are treated by community-based oncologists, but reporting to the hospital’s TR has been problematic. We asked about barriers to treatment measurement and reporting, and sought suggestions to improve these processes. We used deductive and inductive methods to analyze interview transcripts.

We found seven management barriers to adjuvant treatment measurement and reporting: process complexity; limited understanding of TR reporting; competing priorities; resource needs; communication issues; lack of supporting information technologies (IT); and mistrust of management. Facilitators included: increasing awareness; improving communications and relationships; enhancing IT; and promoting the value of measurement and reporting. Four factors deemed critical to successful improvements were organizational commitment, leadership support, resources, and communication.

Organizations striving to improve cancer care quality must overcome key barriers, especially those involving gaps in understanding and communication. In practice, hospitals should make explicit efforts to educate physicians and administrators about the importance of treatment reporting, and improve communications between the hospital’s TR and physicians to ensure that needed adjuvant therapies are appropriately delivered.

INTRODUCTION

For women with early-stage breast cancer, post-surgical adjuvant treatments including local (radiation) and systemic (chemo- and hormonal) therapies have been shown to improve both...

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disease-free and overall survival (Clarke, Collins, Darby et al. 2006; EBCTCG 2005; Howell, Cuzick, Baum et al. 2005). Radiotherapy (RT) following breast-conserving surgery reduces the risk of recurrence by two-thirds (27% to 9%) (Clarke et al. 2006). Chemotherapy reduces mortality by 27% in women under 50 years of age, and by 11% in women aged 50 to 69 years (EBCTCG 2005). Similarly, hormonal therapy such as tamoxifen or aromatase inhibitors (Howell et al. 2005) reduces mortality by 31% among women with hormone receptor-positive tumors (EBCTCG 2005; Howell et al. 2005). Given these compelling findings, the National Institutes of Health (NIH) issued early-stage breast cancer treatment guidelines by the mid-1980s (NIH 1985), and these adjuvant therapies are now considered standard. Yet despite evidence that these treatments are effective, ensuring that adjuvant therapies are provided is difficult, and the level of breast cancer care quality has been found to vary considerably from established guidelines (Bickell, Wang, Oluwole et al. 2006; Griggs, Culakova, Sorbero et al. 2007; Hershman, McBride, Jacobson et al. 2005; Hewitt and Simone 1999; Malin, Schneider, Epstein et al. 2006).

The American College of Surgeons’ (ACoS) Commission on Cancer, a consortium of professional organizations devoted to improving survival and quality of life for cancer patients through standard-setting, research education, and monitoring comprehensive care quality (ACoS 2012a), recently implemented a new reporting requirement for breast cancer adjuvant treatment. This new requirement mandates reporting of primary post-surgical adjuvant breast cancer therapies, reflecting recognition that data on actual practice is the necessary building block for quality improvement efforts (ACoS 2012b). Under the new requirement, RT following breast-conserving surgery, chemotherapy for estrogen receptor-negative tumors, and hormonal therapy for hormone receptor-positive Stage 1c, 2 or 3 tumors must be administered or considered and these adjuvant therapies are now required to be reported as part of the ACoS accreditation process (ACoS 2012b). Such data about adjuvant therapies are usually tracked and assembled by hospital tumor registries (TRs), and are typically reported to state or federal departments charged with keeping the public’s health. In addition, hospital administrators use these data to inform clinical and research activities.

We designed this study to assess barriers to breast cancer adjuvant treatment measurement and reporting to the hospital TR in a large, high-volume breast cancer, urban hospital that treats patients from the wealthiest and poorest neighborhoods, and to explore opportunities to reduce these barriers. We were interested in the perspectives of both community- and hospital-based cancer physicians with respect to measurement and reporting of breast cancer adjuvant therapies, recognizing that the costs and benefits to these different practice organizations may require different approaches to improve current reporting and subsequent practice.
METHODS

Research Design

We designed a comprehensive qualitative study (Maxwell 1996) to examine administrators’ and physicians’ perspectives about measurement and reporting processes for breast cancer patients’ adjuvant therapies. We conformed to the standards of rigorous qualitative research (Crabtree and Miller 1999; Miles and Huberman 2004), and paid special attention to in-depth interview techniques (e.g., McCracken 1998).

Study Setting

Our study was conducted at a large, urban teaching hospital with a high volume of breast cancer patients. The hospital was striving to achieve the necessary standards for ACoS accreditation and therefore was interested in improving information exchange processes. The single hospital locale included 19 medical, 3 radiation and 23 surgical oncologists who treat breast cancer; 75% of the providers were part of community-based solo and group practices, and 25% were providers in hospital-based faculty practices and resident clinics. All providers and practice sites were located within the same urban area.

Key Informant Interviews

Data were collected through in-depth interviews with key informants in both inpatient and outpatient settings. Interviews lasted an average of 50 minutes, and ranged from 30–90 minutes. One study investigator conducted each interview, with a co-interviewer typically available to assist. All interviews were recorded, transcribed, and then verified and corrected by one study investigator. Human subjects approval for this research was provided by the Behavioral and Social Sciences Institutional Review Boards of The Ohio State University and the Mount Sinai School of Medicine.

To facilitate the interview process, we used semi-structured interview guides that included both open-ended questions and follow-up questions to probe for more detailed information. We used interview guides tailored by informant type (i.e., physician, leadership, administrative staff, and tumor registrar) to enable more appropriate focus in the interviews. All guides included four general interview domains: Introduction and Background; Organizational Change and Change Processes at Mount Sinai Medical Center; Cancer Treatment Measurement and Reporting; and Moving Forward with this Research. These domains were selected to organize questions about breast cancer measurement and reporting in the context of quality improvement and organizational change. For instance, questions around organizational change sought to explore potential facilitators and barriers to change that associated with past change efforts that might be relevant to the hospital’s efforts to improve breast cancer treatment measurement and reporting (e.g., Can you tell me any stories about how you’ve been involved in formal organizational change programs within Mount Sinai Medical Center? What went well? What challenges did you experience?). In our analyses for this paper we focus on barriers and facilitators to breast cancer treatment measurement and reporting that emerged as responses to questions about other organizational changes, organizational communication processes, and competing priorities. We also incorporated analyses of interviewees’ specific responses to the question, “What three (to five) things need to be done to improve measurement and reporting at Mount Sinai Medical Center?"

Analysis

Our analytic approach used a combination of inductive and deductive methods. As the study progressed, we read and discussed interview transcripts and preliminary findings, using a grounded theory approach (Glaser and Strauss 1967; Strauss and Corbin 1998) to guide our
exploration of the data. This iterative process allowed us to explore emergent themes in the data, and enabled us to verify these themes as we interviewed additional key informants. For instance, after early interviewees included discussion of implementation of an electronic health record system in the hospital as an example of change, we introduced question probes about the issue of availability and access to information technologies in the context of improving breast cancer treatment measurement and reporting processes in subsequent interviews.

When we had completed all interviews, we created a coding team that included the lead qualitative investigator (ASM) and a research assistant. This team then reviewed interview guides and transcripts to identify broad themes and issues from the interviews. The coders conferred to produce an agreed upon list of codes and a coding frame. This preliminary coding process allowed us to organize our data into categories of findings (Constas 1992). We then applied our coding frame to three common transcripts, enabling us to compare individual coding decisions and clarify codes and emergent themes within the data. Coders continued to hold scheduled calls to permit regular discussions about the analytic process and ensure consistency of coding. These frequent conversations also helped us reach agreement about final themes we saw emerging from our data. We categorized the themes we report in this paper based on responses to direct questions about barriers and facilitators (e.g., What do you believe are the major barriers to timely and accurate treatment measurement and reporting?), and responses to other interview questions that involved discussion of emergent issues that we classified as barriers and facilitators (e.g., complex process, limited understanding, mistrust). We used the qualitative data analysis software program Atlas.ti (version 6.0) to assist us with the coding and analysis process (Scientific Software Development 2009).

RESULTS

Population Studied

We interviewed 31 administrative and clinical informants at the study hospital and in associated community practice sites. Our key informants included medical, surgical and radiation oncologists, and administrative representatives in multiple practice settings. Across sites we interviewed hospital executives and hospital medical directors (n=6), hospital administrative directors (n=4), hospital-based oncologists (n=5), hospital-based cancer administrators (n=4), community-based oncologists (n=4), the office staff of community-based oncologists (n=5), hospital-based information technology managers (n=2), and the hospital tumor registrar (n=1).

Barriers to Breast Cancer Measurement and Reporting

Seven management-related themes emerged from respondents’ answers to questions about barriers to breast cancer measurement and reporting. Below we describe each of these barriers in greater detail, and we present additional evidence supporting these themes, by respondent type (i.e., community-based physician vs. hospital-based physician vs. administrator or office staff), in Table 1.

1. Complicated Measurement and Reporting Process—One issue that was salient across informant groups was that the complicated nature of the measurement and reporting process itself created a barrier. As one physician summarized, “We don’t have a standardized way of following up with patients, especially breast cancer cases. Breast cancer patients have a lot of doctors so they sometimes pull out with one doctor and follow up with one or two others.” Administrative interviewees also described this complexity: “we are not only dealing with the office, we deal with numerous facilities when it comes to the patient.”
2. Limited Understanding of the Reporting Process—The second barrier involved a limited understanding of the TR and the TR reporting process and was also noted by interviewees across groups. As one community-based oncologist explained, “If there is any reporting, I don’t mind doing it, but there is no mechanism for me to do it. Do I call you up and say, ‘oh by the way I have a new breast cancer patient?’ I don’t even know what to say.” A number of hospital-based physicians were similarly confused. One summarized, “I get nothing from the registry. I have no idea what they do, who they are, or how it benefits us.”

3. Competing Priorities—A third barrier was related to the need for all types of respondents to manage competing priorities. For both community- and hospital-based physicians, interviewees noted how the additional tasks required to properly track adjuvant therapies were often perceived as just “one more thing to do” in already busy practices. As one community-based physician commented, “anything else that adds to the reporting burden slows us down in terms of being able to do the patient treatment and get it done.” Hospital-based physicians noted similar frustrations, noting how some things were missed “because of dealing with the more pressing clinical issues like the actual patients’ care.”

4. Resource Constraints—Across informants, resource constraints appeared to pose another important barrier. As one community-based physician explained, “I am pretty stretched. I guess I can expand my hours, but then I would have to hire different people because my staff, my small staff, have a life outside my office, as they pointed out once.” Hospital-based physicians echoed these concerns, and administrative representatives were also similarly constrained. One reflected, “You know, people are sometimes resistant because it’s going to be more work for them, so some of those resources are really beyond the scopes of the department to make it work.”

5. Communication Issues—A fifth important barrier involved issues related to communications, but different opinions were expressed by each respondent group. Contrasting views were particularly evident when comparing the perspectives of both types of physicians and those of the tumor registrar, especially around the issues of information requests and the flow of information about breast cancer patients. Several hospital-based physicians noted that they had never received requests for information from the TR, and another commented, “I get very few. I guess there should be many, many more.” The hospital’s TR, however, noted that requests were sent: “We’re definitely sending them, so from the time it’s mailed then it gets to the assistants in the office and it makes the physician’s desk. Some of them have their PAs fill them out, so that may be where it’s going. I don’t know.” This communication barrier was summarized by a hospital-based physician who reflected about how the process could break down: “Let’s assume that you send an email. They [the surgeons] are busy; they are in the operating room that day. I [as a surgeon] don’t look at my email until late at night. And then at home, ‘OK, I’ll do it tomorrow.’ And then tomorrow, I forget and they [the TR] don’t get it.”

6. Information Technology (IT) Limitations—Across respondents, the lack of IT systems that supported or could support adjuvant therapy measurement and reporting was consistently reported as a barrier. As one community-based physician explained, “Reporting is basically what I write on the paper. The problem you’ve got is it’s all paper-based….it’s very primitive.” A hospital-based physician echoed, “Nothing is electronic. Everything is paper.” As a result of these IT limitations, both types of physicians described low-technology approaches to tracking patients for needed therapies (e.g., “I use a yellow magic marker”), but these low-technology approaches were not flawless with respect to complete tracking of adjuvant therapies. As one physician explained, “I would only know if I got my
schedule and that patient didn’t show up. But if that patient didn’t schedule, I wouldn’t know that that patient didn’t show up.”

7. Mistrust of Management—The seventh management barrier was mistrust. This mistrust was apparent in each respondent group, but with different areas of emphasis. Community-based physicians expressed concerns about the inability to retain their own patients once patients had been referred to the hospital, and about their ability to remain independent practitioners. As one explained, “Well, one of the things is that they’re [the hospital and its employed physicians] beginning to isolate us. At least this is the way I see it. Because if we don’t get referrals from the hospital, do you know what I’m saying? You get more and more isolated.” Hospital-based physicians also mistrusted hospital management, but their stated frustration was with whether the hospital was truly listening to their concerns and looking out for their interests as faculty physicians.

These areas of mistrust were recognized by hospital administration, who similarly noted mistrust was a barrier. For instance, the concerns of community-based physicians were recognized when administrators speculated about the hospital now being seen as a threat to office-based practitioners. As one administrator reflected, “I think for the first time possibly in our history, people see a credible threat, if you will, from a real institutional cancer program at [this hospital].” Another noted, “they’ve [community-based physicians] openly complained that full-time faculty are displacing them in terms of internal referrals and, for lack of a better phrase, market share.” Administrators also commented about tension with hospital-based physicians. One commented, “I hear a lot from the faculty that they don’t feel like the hospital administration understands or listens to what they need.” Another described how in the hospital, “It’s a little bit like a feudal system, everybody has their own kind of area and their program.” Consistent descriptions of these competing agendas and trust issues from all respondent groups thus led us to characterize mistrust as an important barrier to change and desired improvements.

Suggested Facilitators to Improve Breast Cancer Measurement and Reporting

When informants were asked to consider facilitators that might improve the measurement and reporting process for breast cancer adjuvant therapies, four main themes emerged from respondents’ answers: 1) Increase awareness; 2) Improve communications and relationships; 3) Enhance information technologies; and 4) Promote measurement and reporting. Several of these facilitators directly addressed the barriers we reported above as they included suggestions that could improve understanding of the reporting process, address communications issues, and increase information technology availability; yet others facilitators also emerged. In Table 2 we present respondents’ comments, by theme and sub-theme, and below we highlight our findings.

1. Increase Awareness—With respect to awareness, two sub-themes emerged from the data: a) the need to increase awareness about the tumor registry itself; and b) the need to increase awareness about the value of TR information. While the first sub-theme directly addresses the lack of understanding barrier discussed above, the additional sub-theme suggests a specific opportunity to improve measurement and reporting by promoting the value of the registry and its data. As one hospital-based physician summarized, “The perception I think many people have of the tumor registry is that it’s useless. That’s a perception that has to change.” With respect to TR data, another interviewee commented about the need “…to sort of make the facility aware of what information that’s available to the institution if requested.”

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2. **Improve Communications and Relationships**—The second major facilitator that emerged also included two sub-themes: *improve communications and interactions with the registrar*, and *improve communications and relationships with community-based physicians*. This first sub-theme directly addresses the *communication problems* barrier previously described, and suggests that respondents across groups may be willing to help resolve communication problems. The second sub-theme, while also involving communications and relationships, addresses the *mistrust* barrier that emerged. As one community-based physician lamented, the hospital needs to take steps to improve these external relationships: “After the [bone marrow] transplant is done, send the patient back. Simple. I don’t want to take care of pre and post, but once the patient is stable, it’s my thing.”

3. **Enhance Information Technologies**—The third facilitator involved IT and had two sub-themes: 1) *the need to improve the availability and integration of IT*, and 2) *the need to improve data and reporting*. This facilitator clearly addressed the *limited IT* barrier described above, and, if successfully implemented, could provide a technological solution that also reduced the *resources needed to support reporting* barrier described above. One community-based physician reflected, “I think the most important thing will be having a hospital system that’s compatible with multiple electronic health records to retrieve information, and having links with our personal computers that are compatible with what’s going on in our office.” Similarly, a hospital-based physician noted, “the only way is going to be via the computer and trying to extricate the data that way.” However, respondents across groups also recognized that introducing IT would involve new costs, and resources, as noted above, were considered a barrier. A community-based oncologist explained, “Even if we were given $40,000 a pop to get an EHR in our practice, it’s a miniscule cost compared to the technician and secretarial time that’s going to be needed to implement it, or the rent for space to put it in.”

4. **Promote the Value of Measurement and Reporting**—The fourth facilitator was the opportunity to promote the value of measurement and reporting for the hospital and for patients. Two related sub-themes emerged: 1) *educate about the value of measurement and reporting*, and 2) *promote the value of ACoS accreditation*. First, both administrators and senior leaders noted that efforts to *educate both providers and administrative staff about the value of measurement and reporting* would facilitate improvement. As one leader commented, “I think there’s a lot of communication and collaboration that has to take place among the physicians and the registrar.” Similarly, the tumor registrar described how, “the biggest part of this will be education to physicians and staff and to the hospital.”

Second was the opportunity to *promote the value of ACoS accreditation*. We found that across the organization, senior executives were clearly aware of and committed to the goal of accreditation. As one senior physician leader commented, “I think it’s a great opportunity. I think we have so many of the things that the ACoS is looking for, it’s just a matter of really pulling things together and changing some of the reporting things to make that a little bit better.” Yet beyond senior leadership, we found that across the great majority of physician informants, there was very little awareness about the opportunity for, value of, or desirability of pursuing ACoS accreditation. One physician noted, “I don’t even know what it means to get accredited by them. What does it mean?” Fortunately, upon learning more about accreditation, physicians were largely positive about the potential. As one physician commented after being provided with an explanation, “So I don’t know if the accreditation would help me, but the process of getting accredited, sure it would make things better.” Thus while promoting the value of accreditation may be a facilitator, raising awareness of this opportunity will also be necessary.
Critical Success Factors

In addition to providing suggestions about how measurement and reporting could be facilitated in this hospital setting, interviewees were asked to describe what they considered to be success factors for improving measurement and reporting of breast cancer adjuvant therapies. Respondents’ answers emphasized four critical success factors: 1) organizational commitment; 2) leadership support; 3) resources (IT, human, financial); and 4) communication. While each of these factors might instead be described as a facilitator, the fact that their importance was repeatedly mentioned across respondents led to our classification of these as noteworthy, thus distinguishing them as critical success factors. In Table 3 we provide representative comments from our interviewees that highlight these factors deemed key to improving measurement and reporting.

DISCUSSION

We aimed to increase understanding of the barriers and facilitators of the information exchange process occurring between cancer physicians and a hospital’s TR in order to inform future administrative and clinical efforts to improve breast cancer measurement and reporting. We found that treatment measurement and reporting are indeed complex, and additional barriers such as limited understanding, resource limitations, communication, and mistrust further complicate the process. Nonetheless, our study results also suggest that many of these barriers can be addressed. From a management standpoint, key factors such as organizational commitment, leadership support, resource allocation, and communication may be critical areas where hospitals can focus energies and help reduce barriers that currently contribute to problems with measurement and reporting of needed adjuvant therapies for breast cancer patients.

In practice, a major challenge to improve the quality of breast cancer treatment measurement and reporting is that much of cancer care is delivered in individual physician offices, with treatments provided by physicians across multiple different disciplines. The ACoS Commission on Cancer goal of requiring treatment-report of primary post-surgical adjuvant breast cancer therapies brings to the forefront the critical role of measuring and reporting proven-effective treatments delivered outside the hospital. Yet while hospitals may increasingly be held accountable for the care provided in out-of-hospital physician office practices, they have variable oversight capacity and ability to change individual physician practices.

Accountability is an area of focus that is undergoing tremendous change in the current health care environment. Accountable Care Organizations (ACOs) are on the rise, and have the potential to improve electronic connectivity between hospitals and affiliated practices, especially by encouraging data sharing across sites to improve care delivery (e.g., Skea and Isgur 2011; Fisher, McClellan and Safran 2011; Walker and McKethan 2011). Such organizations share risk and potential savings, thus providing incentives to work together. However, this movement may also be perceived as a threat to the independent practitioner’s livelihood, a concern raised by several physicians we interviewed. If physicians’ and hospitals’ goals are aligned to improve cancer care, efforts to improve treatment reporting to a TR are more likely to succeed. Indeed, until physicians and practice administrators embrace the paradigm shift embedded in integrated delivery systems and ACOs, namely, hospital ‘hubs’ surrounded by community practice ‘spokes,’ the ride toward improved quality will be bumpy.

The keystone of accurate data reporting to clinical registries continues to grow in import and value. Under the 2010 Patient Protection and Affordable Care Act, the Patient Center Outcomes Research Institute was created to help stakeholders make informed decisions.
Informed decisions should be based on evidence which historically relied on randomized controlled trials (RCTs). However, given both the monetary and time costs to conduct RCTs, it is unlikely that multitudes of trials will be conducted to answer the plethora of permutations of clinical questions relevant for individual patients. Rather, comparative effectiveness research (CER), an approach using observation data to compare the benefits and harms of different interventions (i.e., tests, treatments) on patient outcomes, will continue its rise in prominence and practice. Yet for valid CER to be conducted, accurate observational data is required, thus the role of clinical registries is foisted to the forefront. In addition, it is expected that insurance companies will use such data to inform reimbursement decisions (e.g., Pearson and Bach 2010; Hirsch, Giffin Esmail, Tuns, Abernethy and Murphy 2011), and this further increases the importance of accurate reporting of data to registries such as the TR.

The results of our study suggest that increasing awareness of the value of TR information and striving to improve communication both within the hospital and with outpatient clinicians will be especially critical. Indeed, both hospital administrators and physicians will need to work together in good faith, with transparency and open acknowledgment of each side’s needs, costs, threats, and benefits to overcome the underlying mistrust and to move forward to improve treatment reporting. Recent changes in hospitals’ and insurers’ payment and delivery structures supporting the development of ACOs and patient-centered medical homes (PCMHs) may indeed provide an opportunity to incorporate IT approaches and leadership incentives that can help improve treatment reporting. However, by specifically focusing efforts on enhancing organizational and physician understanding about the TR, its data reporting requirements, and the value of the data it can provide, hospitals and health systems can make strides towards improving treatment measurement and reporting, and, as a result, ensuring that breast cancer adjuvant treatments are delivered to patients in need.

Limitations

Our study is limited in its focus on a single hospital setting, thus it may be difficult to generalize our findings. Nonetheless, this site was distinguished by having a high volume of patients with breast cancer treated by both hospital- and community-based physicians, and patients treated included those with private insurance, Medicaid, and other types of coverage, providing additional variability. Further, interviews with multiple types of informants enabled us to study a variety of management issues from multiple perspectives, and to obtain information about challenges such as communications both within and across organizational boundaries that enrich our results.

While our study results provide suggestions about how to facilitate improvements in measurement and reporting, this study was not designed to demonstrate that these facilitators would be effective. The persistence of the themes and sub-themes we report across respondent groups would indicate that these facilitators would be salient in other settings, particularly for conditions of import to the public’s health that rely on registry reporting, and for treatment of those conditions that could benefit from improved communications across disciplines. While the identified facilitators may be effective, we do not have evidence to support their use. Our results instead emphasize that the measurement and reporting process is indeed complex, and both help improve our understanding about the barriers that hinder these processes, and of management-oriented facilitators that could improve an important aspect of delivering needed breast cancer adjuvant therapies.

Future Work

We hope to be able to test the solutions suggested by our respondents in future work evaluating the impact of new measurement and reporting processes in similar urban hospital settings.
settings. Future research will benefit by combining both quantitative and qualitative data to further examine issues around improving the delivery of breast cancer adjuvant therapies in realistic practice settings such as that studied here.

CONCLUSIONS

Healthcare organizations attempting to improve cancer care quality and meet reporting requirements for accreditation and reimbursement must overcome considerable barriers to measurement and reporting about breast cancer adjuvant therapies. Making efforts to increase organizational and clinical understanding about the importance of measurement and reporting and the role of the hospital’s TR in supporting these processes can help facilitate improvements in breast cancer care. By considering management interventions such as explicit educational programs and dedicated efforts to improve communications with the hospital, the hospital’s TR, and both hospital- and community-based physicians, improvements to measurement and reporting will become more visible priorities of the organization, making the delivery of needed adjuvant therapies more likely in clinical practice.

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REFERENCES


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<th>Identified Barrier</th>
<th>Community-Based Physicians</th>
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<tr>
<td>1. Complicated Measurement and Reporting Process</td>
<td>I have to hope the patient has the information about what’s happened to them prior to seeing me. If they don’t I then have to have XXX call up and hope that the pathology reports, the X-rays, the laboratory reports that have been done on this patient are available to me, and if they aren’t, it takes a lot of time and effort on the office’s part to try and track me down.</td>
<td>But sometimes it’s not a patient I’m really caring for on an ongoing basis in my day clinic patient my name got attached to, and it never seems to be the patients that I know really well. I have no idea how they’re getting chosen. It is not uniform at all.</td>
<td>We can have a patient that comes in at stage two and was seen by this doctor and that doctor, and that’s it, they begin the treatment and that’s the whole story. And we can have a patient that we’ve had here for seven years that’s had… they’ve had remission, had surgeries. It just all depends on the patient and their situation. You can have letters from different doctors, and you have to see, … What was given here, what was done here?</td>
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<td>2. Limited Understanding of the Tumor Registry Reporting Process</td>
<td>Except for that little thing I found in my spam folder, I wouldn’t even know that there was any reporting to do. I don’t know if they are obligated to send this out to us or what.</td>
<td>I get requests. I never understand why they’re picking what. I don’t even know if they keep treatment records. Probably not, right?</td>
<td>I don’t know what they are being asked to report on. If they are being asked to report on who are they being followed up with, when was the last time you saw them?</td>
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<td>3. Competing Priorities</td>
<td>We are getting busier. Things are not slowing down, they are picking up. The demand on time is an issue, I would say. Whatever you ask the doctors to do takes time. … to the office certainly there’s a cost.</td>
<td>When you’re continually asked to do one more thing and one more thing and I think things like this tend to fall to the wayside. …you get busy, you move on, and then you have another crazy day, and another month goes by.</td>
<td>… it’s hard because I lack staff so most of my time is spent just keeping with compliance. … there’s so many other things going on.</td>
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<td>4. Limited Resources to Support Reporting</td>
<td>So I don’t have anyone to do that for me except myself. We have been wanting to add someone, but the way reimbursements have been going … “so I don’t mind doing it, but my resources are extremely limited. I am already stretched.” We just don’t have the physical space to keep five years worth of charts. … Because it costs us per month for every cart.</td>
<td>… you need people power. And I mean with the way medicine is going now, you know? We try to do more with few, do you know what I’m saying? With less. You know, we’re not hiring data managers…we wouldn’t be able to afford it. We don’t have NPs. We don’t have the resources for that.</td>
<td>…to provide that documentation for every breast, we would actually need another body, another person, someone who can keep track of what’s going on with a particular patient— It’s just the man-hours at this point in time to do it.</td>
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<td>5. Communications Issues</td>
<td>But no one called me…All I need is one phone call. I don’t mind filling out the form if the form came in, unless there is some disconnect at the front desk. Then it doesn’t get anywhere.</td>
<td>You can’t directly communicate with other departments. It’s really annoying. I have to say there’s e-mail exhaustion. There is a glut of e-mails.</td>
<td>…physicians were telling me they were not the managing physician. Then we would have to go back and re-review the abstract that was partially the problem, then we would go back and we would say, ‘Well no, you are the managing physician.’</td>
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<td>6. Limited Information Technologies</td>
<td>I read the form, I open the chart, enter the information and it goes back in the envelope that’s pre-addressed and pre-stamped. If it’s not in my head, like an active patient, I have to refer to the record.</td>
<td>So it is very labor intensive to go through the chart every single time. Well I mean the office isn’t that large. … So we know if someone doesn’t come then we know that someone’s missing and then we’ll call them.</td>
<td>If this could be electronic it would really make our lives much easier. …ideal if a lot of this information could be downloaded into our database … so we could clearly identify which patients received chemo as opposed to looking through a long list of medications.</td>
</tr>
<tr>
<td>7. Mistrust</td>
<td>Well I mean what’s happening is that, and I know they’ll never admit it… The full-timers have been told to send to other full-timers and so therefore the patients are not being sent. …</td>
<td>I think it’s very, very financial. I think that the whole trust-control issue is bottom line related to reimbursement, and whether or not the hospital is really going to</td>
<td>I’m not sure if there’s a bit of an organizational distrust in the systems and in the spirit of the endeavor. …</td>
</tr>
</tbody>
</table>

Table 1
Barriers to Measurement and Reporting for Breast Cancer Patients, By Respondent Group

**RESPONDENT GROUP**

1. Community-Based Physicians
2. Hospital-Based Physicians
3. Administration and Staff
### RESPONDENT GROUP

<table>
<thead>
<tr>
<th>Identified Barrier</th>
<th>Community-Based Physicians</th>
<th>Hospital-Based Physicians</th>
<th>Administration and Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>they’re not going to send their patient outside the institution…</td>
<td>capture those charges, and where is it going to get posted, and what’s going to be the tax on the faculty…”</td>
<td>So the challenge here has been building the kind of confidence that’s required for people to really integrate those programs in a meaningful way.</td>
<td></td>
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</tbody>
</table>
## Table 2
Suggestions to Facilitate Improvements in Measurement and Reporting

<table>
<thead>
<tr>
<th>Theme Sub Theme</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Increase Awareness</strong></td>
<td></td>
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<tr>
<td>Increase Awareness of Tumor Registry</td>
<td>“I think it’s more of an awareness of why they have to do this. I think that may be a big part of the problem… the ‘why are they getting letters, ’ what’s the purpose of this?” “They have to understand why tumor registry is important and how we all contribute to their success or their failure.” “XX has been really working with the registry to understand what it is that we do. She has a true appreciation for the time that we’re spending and I think she will be the person to push the awareness of what the cancer registrar is and what cancer registry can offer to the institution as a whole. Prior, we were just data collectors.”</td>
</tr>
<tr>
<td><strong>Enhance Information Technologies</strong></td>
<td></td>
</tr>
<tr>
<td>Improve Availability and Integration of Information Technologies</td>
<td>“If you can do things electronically… when I get home after I have dinner, I am a renewed man, if I go onto my computer it takes another 15–20 minutes I don’t mind. I would do that.” “I mean the tumor registry cannot be a distant relative, for example. It just has to be an integral part of what we do here.” “There’s so many different ways that we [IT] can certainly help the tumor registrar, but if I don’t know what they need, I don’t know.”</td>
</tr>
<tr>
<td>Improve Data and Reporting</td>
<td>“…we have to sort of come up with categories that we need to label so that we could run reports that are going to be beneficial for clinical practice and still collect your financial data versus the other way around.” “…if they want to track a particular regimen 20 patients who received cytoxan, what is the life expectancy of this patient after three years, we would have that information. But we need to get that information from physicians in order to be able to supply them with that.” “I’d like to learn something from this that’s not just for my institution and for my reporting requirements, so that our breast cancer researchers learn something about why this is happening to our patients here… when you create databases of patients in your system, you can study them and learn something more.”</td>
</tr>
<tr>
<td><strong>Promote Measurement and Reporting</strong></td>
<td></td>
</tr>
<tr>
<td>Educate about Importance of Measurement and Reporting</td>
<td>“I think what you do to do is you first have to educate the doctors about the need for this information. I think you have to really educate the doctors about how not collecting this information impacts upon the lack and quality of care we give our patients.” “…education around the importance of documentation is one element…because I think that’s really just not up to par with what I think the national standards call for.” “I’d like to get two for one - get this data, it’s going to take a lot of energy, time, and money, and then what else can we learn from this? Let’s not bury it in some registry in the basement, but let’s use it for some opportunity to otherwise study and learn from our patients.”</td>
</tr>
<tr>
<td>Promote Value of ACoS Accreditation</td>
<td>“For us it’s a minimum certification, a minimum requirement that we have to meet to be seen as a comprehensive cancer center. There’s no choice. We made a board level commitment around becoming a comprehensive cancer program.” “If you are going to really put resources toward your cancer program, it’s one of the important milestones.” “We are the only hospital [in this geographic area] that’s not accredited by the College.”</td>
</tr>
</tbody>
</table>
### Table 3

#### Critical Success Factors

<table>
<thead>
<tr>
<th>Factor</th>
<th>Representative Comments</th>
</tr>
</thead>
</table>
| **Organizational Commitment** | • “… it has to be a priority. …For the institution.”  
   • “… when you have that kind of commitment at the top, then the change always happens.”  
   • “right at the very top [name] has a real commitment to putting in the investment and the systems which are necessary. The top … there’s a commitment. … there’s a commitment to building a topnotch program.”  
   • “I think when there’s a mandate from above and they put money behind things to fund it happening I think they happen.” |
| **Leadership Support** | • “support from the executives is the most important thing.”  
   • “Making sure that it’s seen as an important thing to the chairman. The chairman, in theory, should be holding the faculty accountable.”  
   • “… if there’s a business owner who was the decision-maker and settles the disputes among the various players in terms of the direction, and then resourcing it adequately.” |
| **Resources**    | |  
| **Data Collection** | • “the people here are capable of doing whatever is needed to be done both from an IT and from a business side of the house. It really just comes down to the resources that are available to focus on it.”  
   • “resources to sort the data and send it out.” |
| **Human Resources** | • “you need to just really stand on top of them and that’s about resources, that’s people, somebody dedicated to that position. Go see them, Can I meet with you? When are you available? Let me come to your office….”  
   • “it would be ideal if I had at least three dedicated people for follow-up, three personnel just dedicated to do follow-up only, because it would be done on a daily basis. We’ll be able to track and see what the issues are with retrieving information from the physicians’ offices internally. We just need dedicated staff to just work on this.” |
| **Financial Resources** | • “There is a certain amount of money, certain list of priorities and depending on who’s budgeting the different priorities... You need to make an investment…”  
   • “Adequate space.” |
| **Communication** | • “I am the hospital administration, I’m listening to what you need. But a lot of time it’s just perception, communication, and visibility. I think you can never really over-communicate with people.”  
   • “… you have to do a blitz so that people realize that it’s really important, it’s so important, look at all the resources they are throwing at it.”  
   • “you basically have to annoy them to get to a point where they realize that it’s not to go away.”  
   • “there is a level of feedback that has to be given to the people involved so that they feel somewhat comfortable.” |