

RESEARCH BRIEF

fragmented care

Almost a decade ago, no less an august body than the Institute of Medicine (IOM) concluded that, “for many Americans with cancer, there is a wide gulf between what could be construed as the ideal and the reality of their experience with cancer care.”¹ In that same IOM Report, the National Cancer Policy Board (NCPB) further noted that

the “ad hoc and fragmented cancer care system does not ensure access to care, lacks coordination, and is inefficient in its use of resources.”

The NCPB went on to assert, “Efforts to improve cancer care in many cases will therefore be local or regional and could feasibly originate in a physician’s practice, [or] in a hospital.” Coordinated care that provides an integrated patient experience, with a clear physician clinical leader, a written *pre-treatment* multidisciplinary treatment plan, as well as an IT network that enables multiple modality physicians to share real-time patient diagnostics and treatment information remains a stretch goal for most community programs. Patient navigators and navigator services, while bridging the fragmentation realities many patients experience, is still recognized as a stop-gap measure that addresses, but fails to solve the *clinical integration* challenges community programs face. Marsha, I wouldn’t put these sentences in orange for the web, I’m just marking them as a way for you to find the changes.

In 2007, the California Healthcare Foundation conducted a study to define how well care is coordinated by physicians (in so-called “gatekeeper” positions) and how well patients feel the healthcare “system” representatives communicate with them.² The Study surfaced the following:

- 40% of (CA) physicians reported that over the past 12 months their patients experienced problems because care was not well-coordinated across multiple sites or providers.
- 21% of physicians reported that over the past 12 months their patients sometimes or often had tests repeated because the findings were not available at the time of the patient’s scheduled visit.
- 57% of physicians reported that it was difficult to compile a comprehensive list of their patient’s medications, including those from other doctors, using their current patient medical records system.
- Almost 1/3 (30%) of physicians say their patients often experience long wait times for specialist/consultant visits.
- 41% of physicians reported problems with receiving referral results; these physicians report they received no referral information for up to half their patients.

¹ Institute of Medicine, [Ensuring Quality Cancer Care](#), 1999.

² California HealthCare Foundation, [Uncoordinated Care: A Survey of Physician & Patient Experience](#), 2007.

- More than 40% of physicians reported that their patient's medical record or other relevant clinical information was not available at the time of a scheduled visit – a lack of coordination of patient information.

The Patient Experience. As frustrated as physicians may be with uncoordinated care and information, patients clearly bear the burden of fragmented (or non-integrated) care. In focus groups, cancer patients especially note the inconvenience of making so many individual trips (visits) to individual physicians' offices, their feeling that “no one is in charge”, or has the whole picture of what's going on with their case, their inability to coordinate multiple physician visits on one day, and their fear when they receive what they see as conflicting information about their health, or their treatment, from different caregivers. As cancer care delivery has migrated away from an inpatient setting (the hospital) and now rests solidly in the outpatient realm, cancer patients find themselves responsible for:

- Searching for information about their disease, treatment options, supportive care, and often prognosis;
- Communicating with their myriad doctors and their staffs; and further delivering information about their case from one physician to another. Answering the question, “What did Dr. Jones tell you about this?”
- Providing the same identification information (and health history) repeatedly to multiple providers and institutions who do not or cannot share such personal health information; and,
- Tracking their own diagnostic test results (often picking them up at the diagnostic center and transporting them to the doctor's office).

TOG Focus Group Findings on Patients' Descriptions of the “Ideal” Cancer Center. For the past ten (10) years, The Oncology Group has facilitated cancer patient focus groups. When cancer patients describe their “ideal” cancer center, this is a sample of what they identify as important to them:

- All services in one facility that is easy to find, with easy parking.
- A team of physician who plan my care.
- All my treatment options are explained to me. Tell me what chemotherapy or radiation therapy entails and be specific.
- Staff who have time for patients, who are experienced and understanding.
- Care coordinators who help the patient through all the hoops and help me understand what is happening.
- Financial counseling and help. “All those forms are confusing and sometimes I don't know how I can pay for everything.”
- Information about support program, at the hospital and in the community.
- A counselor – not everyone is a “group” person, but we still need support.
- Complementary programs – massage, acupuncture, prayer.
- Classes to help me with life after cancer – transition to being a survivor. Rehabilitation to get me back to normal.

Intra-Practice Coordination, Sequential Multidisciplinary Care & Inter-Practice Coordination. Physicians often accurately assert that care within their individual practice is coordinated, that staff are helpful, and function as navigators to assist the patient through the system, *while under the care of their practice*. The Oncology Group has found such intra-practice coordination to be the norm in most well-run community cancer programs. The lack of care or information integration is often most evident at the point of “hand-off” or

transition to another modality or caregiver. For example, patients experience fragmentation post-surgery as the surgeon “hands off” the patient to a medical oncologist. Then another jolt often occurs at the point of sequentially handing off the patient to radiation oncology. So, the standard private practice approach of sequential movement through a series of physicians, modalities, staffs, and practice locations stands in stark contrast to what patients experience when they encounter a coordinated care model. In a seamless care model a team of physicians examines the patient and their medical records at one time, on one day, presenting the patient with a written treatment plan that all this patient’s physicians contributed to and agree with. Most physicians and patients can describe the “perfect” experience. Creating this experience, in a private practice community hospital setting is the challenge. But more community cancer programs appear to be successfully meeting that challenge in this 1st decade of the 21st century.

Who’s To Blame For Fragmented US Healthcare Delivery? It is important to note neither physicians nor hospitals are the villains in the fragmented care delivery system in the US. Market forces, including competition (increasingly doctor-hospital competition), expanding technology ownership through access to capital, CMS (and other insurers) reimbursement regulations, physician and nursing shortages, malpractice insurance rates, Stark regulations, and corporate practice of medicine laws all contribute to the fragmented US system of healthcare. The entire US political and business culture and traditions contribute to the current fragmented medical care delivery model US citizens function with.

IOM Solutions & Recommendations. So, what can be done, at the local level, in the near-term to improve each patient’s experience while undergoing cancer treatment? The IOM suggests individuals with cancer need:

- Recommendations about initial cancer management, which are critical in determining long-term outcome, be made by experienced professionals.
- Confidence in the experience and training of their providers;
- An ability to ask questions and voice opinions comfortably, to be full participants in all decisions regarding care;
- An agreed-upon prospective care plan that outlines the goals and the process of care.
- A healthcare professional responsible and accountable for organizing this plan in partnership with each individual.
- A mechanism to coordinate services;
- A feeling that providers respect them, listen to them, and advocate on their behalf;
- Psychosocial support services and compassionate care;
- Policies that ensure full disclosure of information about appropriate treatment options;
- Assurances that agreed-upon national standards of quality care are met at their local site of care; and
- Access to high-quality clinical trials.

The Facility Solution . . . And a Caveat. A number of cancer programs build a Cancer Center facility to reduce the patient’s experience with fragmented care, decision-making and communication. And this approach can be successful. No doubt, the “corridor effect” which occurs when two professionals meet casually in shared space and end up discussing a patient reaps unmeasured results. But there is a caveat to this approach – more than one Cancer Center facility has been built, however, no (or few) cancer-related physicians chose to move their practice into the building. And it remained a Cancer Center in name only. The Oncology Group supports building a Cancer Center, as long as appropriate physician practice occupants are secured long before groundbreaking.

NCCCP Field Advances. Since 2007, representatives from select community hospitals who participate in the National Cancer Institute program NCCCP (National Community Cancer Centers Program) have identified and defined key infrastructure elements and characteristics that produce more integrated treatment planning and delivery, while mitigating the real-world exigencies of community cancer care. The NCCCP team has identified five (5) levels of multidisciplinary care/clinics along a self-graded Matrix (Assessment Tool). This MDC Matrix Assessment Tool is available to the public, on the NCCCP website. It provides an evaluation tool that addresses key integrated care elements. These elements include case planning synchronicities; physician engagement and cohesion; episodic vs. coordinated care delivery models; contiguous infrastructure (physical facility); aligned financial futures; early access to clinical research; and shared EHRs. Marsha, again, not suggesting this section be called out for the web, I just wanted you to be able to find my additions easily.

What Can a Program Do to Provide a More Integrated Patient Experience? TOG suggests the following are key approaches to creating a more coordinated cancer care experience for the majority of cancer patients:

1. Use the NCCCP MDC Assessment Tool to evaluate and identify which integration level describes the hospital's current care delivery situation.
2. **Create interdisciplinary treatment planning opportunities** that meet private practice schedules and reimbursement realities, for the top four (4) cancer diagnoses. Evaluate the hospital and medical staffs ability (and interest in) providing a multidisciplinary clinic option (MDC).
3. **Ensure that each patient receives a *written* multidisciplinary Treatment Plan** prior to any treatment (including surgery).
4. **Hire and train adequate numbers of Patient Navigators;** and authorize these individuals to flow between practices and hospital-based services.
5. **Institute an EMR across key practices and the hospital** to ensure patients' information is shared through the system, not via the patient acting as messenger between practices.
6. **Standardize paper H&P documents and create a legal approach to sharing patient's history, diagnostic and treatment information** (in the interim to installing an EMR).
7. **Investigate local approaches to collapsing barriers to communication & patient flow-thru between modalities, offices, and hospital departments.**
8. **Build a multidisciplinary Cancer Center building** (noting the physician occupancy caveat).

Each cancer program operates with its individual set of success criteria. And no single cancer program (or even regional consortium) can single-handedly solve the myriad and historical barriers to coordinated, integrated care in this country. The Oncology Group suggests however, that just as the National Cancer Policy Board noted in the IOM Report, "Efforts to improve cancer care in many cases will therefore be local or regional and could feasibly originate in a physician's practice, [or] in a hospital."