

The Quality of Cancer Care:
Models of Excellence

A proposal submitted to the National Cancer Policy board
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Executive Summary

The available data show that small sections of cancer care can be improved, with better patient outcomes and often cost control or even savings. Regional palliative and routine cancer care networks have shown modest improvements in outcomes with cost savings. Within single institution pain control, intensive care unit use, and disease management can be improved, again with better quality and with cost savings. However, there are no published data on attempts to systematically improve an entire system of care.

The panel of experts is convinced that processes, outcomes and financial outcomes can all be improved. They are in agreement that a full range of services must be available to patients, but most believe this does not need to be in location or even all within one health care system. All argue for multi-disciplinary group approaches in the clinic, both to improve care and to use group process to standardize care. A uniform part of their approach is the necessity of practitioners to standardize their care, track outcomes, and receive feedback on performance. Scotland has moved ahead to limiting cancer care to those practitioners who will agree to evidence based guidelines, and submit their results to external scrutiny; full results of the first three years of that program will be available in 1999. No country, state, province, or center is near to making a similar commitment.

One universal model of excellence was proposed by many of our consultants, and has these major characteristics: 1. Ease of access by patients and referring doctors. 2. All specialties available as needed, but not necessarily on site. The “silos” of radiation oncology, medical oncology, surgical oncology should be transparent to the patient. 3. There is an accountable physician at any given time. 4. Outcomes and processes are tracked and reported. Quality assurance and accountability are easily documented. 5. Cost of care is worked out to the point that case rates for broad episodes of care are acceptable. 6. Patients and professionals have access to information in the office and via the Web. Patients can call in anytime or send e-mails and get answers to routine and complicated questions. 7. A written treatment plan or pathway is available at all times for patient and physician review. Internal communications structures emphasize the treatment plan based on best evidence. 8. Follow-up strategies are simplified to reduce travel and hassles for patients following treatment. 9. A consistent and compassionate approach to end of life care is in place, with limits on palliative chemotherapy and/or appropriate use of hospice. 10. Advanced directives are raised early in the course of the illness and reviewed on a regular basis. 11. Clinical trials are offered to all patients.

There are major barriers to implementing each of these steps, including but not limited to the following: 1. The current reimbursement system, which is predicated on use of chemotherapy and radiation. 2. The entrepreneurship needed to make major changes in a system that performs reasonably well for many. 3. The additional skills of patient education and counseling that would be needed. 4. The lack of community “buy in” to limits on health care for serious illnesses.

Introduction

The charge: Models of Excellence in Cancer Care

The National Cancer Policy Board, as part of a project on quality of care, sought information on models of excellence in quality care. While difficult to define, for many consumers, excellence would be achieved if throughout the cancer care experience there were the following:

- a feeling of confidence in the experience and training of their providers,
- an awareness of all treatment options and the risks and benefits associated with each,
- a clear understanding of the diagnosis and treatment plan,
- access to comprehensive and coordinated services,
- an ability to comfortably ask questions, voice opinions, and be a full participant in all decisions regarding care, and
- a feeling that providers respected, listened, and advocated on their behalf.

The American College of Surgeons Commission on Cancer and the Association of Community Cancer Centers are among the organizations that have developed quality standards for cancer programs that operationalize some of these signs of excellence. The Board wished to obtain case studies of cancer care delivery systems that illustrate excellence in integrating the many aspects of cancer care in innovative ways (e.g., early detection, diagnosis, development of a treatment plan, implementing treatment plan, survivorship care, and end-of-life care). The case studies would describe these components:

- development of the model,
- identify key elements that make the model a success, and
- potential impediments to generalizing the model to other care settings.

This is a tall charge. There are no easy solutions, and likely to be unforeseen problems in each new solution. Contrast the above system with any personal or family experience in the health care system, and there are likely to be discrepancies. Yet, as national consultant Dr. Gary Lazar noted, “Every oncologist believes they are providing the very best care available.”

As described at the initial meeting of the Institute of Medicine National Cancer Advisory Board in April 1998, there is virtually no peer-reviewed, reliable information on what constitutes a “model of excellence” cancer program. What follows is an attempt to show what such a program should entail, and how such a program might be measured in the future.

This report will have four sections: I. Background on possible models. II. Review of the available literature. III. Interviews with leaders in the field. IV. Summary. And V. Recommendations.

Section I: Background on possible models

The need for improvement

There are some identifiable problems in cancer care today. These might include, but not be limited to the following:

- High costs, with costs escalating from \$35 billion to one estimate of \$50 billion in several years. The Wall Street Journal reports 8-15% medical inflation in Minneapolis, home of “mature” managed care, in 1998.¹
- Poor coordination of care, often alleged but not often reported. (Who would write that report on their own center?)
- Fragmented end of life care, with late referral to hospice^{2,3} and inadequate pain control even by oncologists⁴⁻⁶
- Clinical trials, the defining nature of oncology, and considered the Holy Grail, used in only 2-3% of patients.⁷
- Substantial confusion about what constitutes appropriate and useful medical care. Does a single promising Phase III trial showing 1 month improved survival in pancreas cancer justify universal use of that drug at \$750/week (plus monitoring costs) in addition to the usual palliative care?
- Variation between doctors in level of aggressiveness beyond what the data might bear. Oncologists in Maryland would use two to five chemotherapy regimens for patients with metastatic breast cancer,⁸ when none have been proven in randomized clinical trials to be better than supportive care.
- Concentration on curative and palliative chemotherapy to the exclusion of prevention, screening, surveillance, psychosocial adaptation, and the burgeoning field of complementary therapies.

The promise of disease management

Disease management has been touted as one approach to comprehensive quality improvement and cost control. Robert Brook has written that “Managed care is not the problem, quality is.”⁹ He goes on to document that perhaps as many as 25% of hospital deaths from pneumonia, heart attack and stroke would be prevented by better inpatient care, and that the death rate can be different by as much as 5 out of 100 patients.

Dr. Bettina Kurowski has written about disease management in oncology, and how it meets the usual criteria of high cost, variations in management, discrete episodes of care. The model focuses on coordination, reaches across subspecialty boundaries, uses guidelines, measures outcomes, and aggregates costs in to episodes. But she notes six areas where cancer illness and treatment are substantially different from other illnesses.¹⁰

First, cancer is not one disease, like myocardial infarction, but hundreds of diseases. Treatments may involve several specialties, such as surgery, radiation, and medical oncology and be spread over time.

Second, long term survival is the goal, so a good program should change the practice of those practitioners who do not perform well on first line, curative treatment. That would need to start before treatment begins, and would require a high volume of curable illnesses for each practitioner. For the most part, however, long term survival and curable illness are not the target. No one really cares how much it costs to cure acute lymphoblastic leukemia in children, or curable Hodgkins disease in adults. The major target for cost reduction is palliative chemotherapy, radiation, etc. where cure is not possible and the differences in outcomes among treatments are expected to be small.

Third, oncology incomes are dependent on interventions. “Chemotherapy is the only commodity sold in large quantities in doctor’s offices in the United States.” Many guidelines would restrict the use of chemotherapy and supportive care upon which current physician incomes are based. For example, in our current practice, billing for chemotherapy could mean the difference between an annual salary of \$220,000 and \$40,000.

Fourth, oncologists depend on treatment to modify the disease, and generally ignore the effects of patient compliance and behavior on the disease process. Some oncologists have been slow to expand to the field of information systems, and these often take the form of marketing tools. In addition there is less proof of efficacy than in diabetes education for example. The target is different here, too. Most disease management models focus on patient compliance, e.g. asthma and diabetes. With oncology it is more likely to be doctor compliance to guidelines, advance directive conversations and the like.

Fifth, the high revenues and profits that can be generated in the current system have encouraged investors to seek maximization of revenue rather than lower-cost disease management. Changes in disease management have been reported to show some dramatic improvements but the data may be proprietary and not available. For instance, coordinated disease management by an expert team is reported to have expanded home care services for AIDS patients by 600% but decreased total costs by nearly 50%; however, there are no actual data in the report.¹¹

Finally, mistakes in cancer management can have dire consequences, such that the fear of litigation or bad outcomes has led to fear of upsetting the status quo.

What is a useable Model for Excellence?

There are likely to be very profound differences in the best model of cancer care, depending on who is doing the design. Patients might want ease of access, expertise, and no out of pocket costs.

Providers would want ease of access, and reliable incomes and autonomy. Insurers would want expertise, measurable quality, and low costs.

One model that would be acceptable to most parties has been proposed by Dr. Chris Desch.

- Ease of access by patients and referring doctors
- All specialties are available as you need them
- The “silos” of care—radiation oncology, medical oncology, surgical oncology—would be transparent to the patient.
- There is an accountable physician at any given time.
- An internal communications structure that emphasizes the treatment plan based on best evidence.
- Outcomes and processes are tracked and reported with quality visible assurance and accountability.
- Patients can call send e-mails and get answers to routine and complicated questions in short order. Patients do not have to decide who to call for what; one phone number figures it all out.
- The cost of care is worked out to the point that case rates for broad episodes of care are acceptable.
- Patients routinely report high satisfaction rates.
- Patients and professionals have access to information in the office and via the Web.
- The physical setting for cancer care is appropriate.
- A written treatment plan or pathway is available at all times for patient and physician review.
- Follow up strategies are well worked out to reduce travel and hassles for patients following treatment.
- Consistent and compassionate approach to end of life care.
- Advanced directives are raised early in the course of the illness and reviewed on a regular basis.
- Clinical trials are offered to all patients.

What would a Model of Excellence look like, and how would it be evaluable?

There is no standard definition, so we made a functional definition:

“a comprehensive cancer care plan that had systematically evaluated the access, processes, and outcomes of care delivered; corrected problems; and evaluated the results.”

II. Review of the available data

Methods

We cross-matched the following terms in Medline: oncology or cancer, with models of excellence, quality of care, and quality assurance. The number of matches made was initially exciting, but on further inspection there were no articles describing a program that had evaluated its mission, found its flaws, developed a plan for fixing flaws, implemented said plan, and evaluated the results.

Table 1: Medline search for models of excellence in cancer treatment

Term	Cross matched term	Number of matches	Number describing proven models of excellence
Oncology or cancer treatment	Models of excellence	0	0
	Excellence	0	0
	Quality of care	1873	0
	Quality assurance	651	0

We next did a directed search of the literature and prior reports, searching for comprehensive programs or smaller programs that attempted to improve care. We report some of the more exciting ones here in three categories: 1. Program proven to improve care. 2. Programs proven to save money. And 3. Programs that improve care and save money.

Model programs

1. Programs that improve care

No specific programs were reported. The few available programs using clinical practice guidelines, care maps, etc. were reported in the Clinical Practice Guidelines Report. Of these, only the British Columbia Cancer Agency and Centre Bernard Lyon reports comment on enhanced quality of care instead of costs.

In British Columbia, which had approved provincial guidelines for care, observed patterns of care for early breast cancer were more consistent than in Ontario during the same time period.^{12;13} During the same time, survival continued to improve for patients with early breast cancer, with an amount equal to that observed on the randomized clinical trials.¹⁴ Although not causal, the association seems strong that provincial standardized care is associated with better disease outcomes.

In France, standardized practice guidelines led to improved compliance with evidence-based care; improvements in typical disease measures like disease free survival have not yet been described. Clinical Practice Guidelines is a regional quality assurance project started by the comprehensive cancer center in Lyon, Centre Leon Berard.¹⁵ In 1993, only 42% of initial treatments conformed to the clinical practice guidelines or were based on scientific evidence, compared to 68% in 1995. Overall, there was a striking increase in the number of decisions

compliant with the guideline or based on scientific evidence, from 19% to 54%, $p < .001$. For colorectal cancer overall, the compliance for the whole treatment sequence increased from 50% to 70%, $p = .009$. In 1993 71% of the decisions were compliant or judged in accordance with the scientific evidence, with an increase to 81%, not statistically significant. The compliance rates did not change except for administration of adjuvant chemotherapy.

This same process was reported at the 1998 American Society of Clinical Oncology meeting to improve compliance rates in a French Cancer Network.¹⁶ The Centre Leon Bernard and 28 hospitals established a regional cancer network. The guidelines were reviewed by all the practicing physicians, then used in a continuing education program of 12 meetings and specific reminders mailed to all physicians in 1995. The compliance rate for breast cancer improved from 12% in 1994 to 37% in 1996; for colon cancer, from 14% to 45% (all $p < .001$). The range of improvements was similar to those reported in the original study, with improvements in diagnosis, surgery, chemotherapy, and radiation. (data not shown) Again, these modest changes in practice were accomplished without formal penalty or reward other than education, awareness, and peer pressure.

2. Programs that save money

City of Hope Pain Management

The City of Hope National Medical Center began a program to prevent unnecessary hospitalizations for pain control, or re-admissions to re-establish pain control. Of 2,977 unscheduled admissions in 1989-90, 255 had a primary diagnosis of uncontrolled pain. Over half of these admissions came within two weeks of a *prior* discharge, and one quarter had a prior admission with the same diagnosis. The group designed a simple three-part program, shown in Table 2.¹⁷

Table 2: Strategies to change culture

Pain resource training program	Nursing staff assumed an active role in pain management. Staff pain experts on each shift and each unit.
Focus of continuous quality improvement (CQI)	Hospital pain control audit and staff survey to check attitudes, and see what educational materials were needed.
Supportive Care Service	Full time nurse clinical specialist for pain/symptom control, part time physician salary support.

They next audited charts from 1992-93. There were 1351 unscheduled admissions, out of a total of 4066, with uncontrolled pain listed as the most common reason for 103 (7.6%). Total re-admissions decreased as shown in Table 3.

Table 3: Re-admissions for pain, after intervention

	1989-90	1992-93
Total admissions	5772	4066
Pain admissions	255 (4.4%)	121 (3.0%)
Length of Stay	11.8 days	12.0 days
Total cost @\$1,666/day (estimated)	\$5,097,960	\$2,378,715

The total cost to the system declined by \$2,719, 245. Not *all* the change can be attributed to the intervention, but some can. For instance, the number of admissions dropped slightly in those years, suggesting that reasons for hospitalization were changing. But the length of stay was higher in the second time period, suggesting that either they were sicker, or some marginal hospitalizations from the prior period had been avoided.

The results should be taken with some caution. One unknown part of the data is that perhaps there were patients who might have benefited from inpatient stays for pain control, who did not get admitted thanks to changing admission standards; the accounting system would have no means of finding such patients. Also, the costs may simply have been shifted to the outpatient setting outside of the means of the accounting system to capture. Such a shifting has been seen in a “at home hospital” program in England with no net savings.¹⁸⁻²⁰

3. Programs that may improve care and save money

Regional Palliative Care Networks

Bruera and colleagues noted an excess of uncontrolled symptoms, and too frequent deaths in the hospital in Edmonton, Alberta. During 1995, they implemented a Regional Palliative Care Program (RPCP) to increase access of terminally ill patients to palliative care, and to decrease in-hospital deaths and lengthy admissions.²¹ The program consisted of an additional 4 full time physicians and nurse consult teams, 56 hospice beds at 3 different sites, and more available home nursing care. Fees for family physician home and hospice visits were increased, and the palliative care team did extensive education. Program costs were estimated at \$6,200,000/year.

All patients in the province were eligible for the program. Data were collected from the Cancer Registry, Health Records Department, Home Care Program, and RPCP office. Results are shown in Table 4.

Table 4: Preliminary results of the Regional Palliative Care Program

Outcome	Pre-RPCP 1992/3	Post 1995/6	P value
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Deaths in acute care facilities/ Total deaths	1020/1215 (84%)	845/1530 (55%)	<.001
Patient days in acute care facilities	25,500	11,830	<.001
Hospice deaths	<100	516	
Patients receiving palliative care	280 (23%)	1087 (71%)	<.001
Cost savings		\$2,500,000	

The data suggest that the RPCP increased access to palliative care, increased family practice physician participation in palliative care, and reduced costs of care. 85% of patients discharged from the cancer center chose to continue care under their own family physician, with the RPCP available as needed. The authors estimated that the program saved the province a total \$2,500,000 due to decreased use of acute care facilities. These savings appear to have been sustained in the ensuing years, and a full manuscript is under review (E. Bruera, personal communication.)

Rural cancer outreach systems

Our own group developed a the Rural Cancer Outreach Program (RCOP) between two rural hospitals and the Medical College of Virginia's (MCV) Massey Cancer Center (MCC) to bring state-of-the-art cancer care to medically undeserved rural patients.²² The financial and clinical impact of RCOP on both the rural hospitals and MCC was analyzed.²³ Pre- and post-RCOP financial data were collected on 1,745 cancer patients treated at the participating centers, two rural community hospitals, and MCC. The main outcome measures were costs (estimated reimbursement from all sources), revenues, contribution margins, and profit (or loss) of the program.

The clinical impact on the measured index conditions appeared to have been favorable. State of the art care, clinical trials, and oncology provider education are now standard at the rural centers.²⁴ Improvements were noted in breast cancer care (use of breast conservation) and pain control (as measured by morphine use.)²⁵

The RCOP had a positive financial impact on the rural and academic medical center hospitals. MCC benefited from increased referrals from RCOP service areas by 330% for cancer patients and by 9% for non-cancer patients during the same time period. The rural hospitals experienced rapid growth of their programs to over 200 new patients yearly, and the RCOP generated significant profits for them which increased yearly. Total profits went up 43% from 1992 to 1993, on collections that increased 40%, showing the growth of the program. The net annual cost per patient fell from \$10,233 to \$3,862 associated with more use of outpatient services, more efficient use of resources, and the shift to a less expensive locus of care. The cost for each rural patient admitted to MCV fell by over 40%, compared to only an 2% decrease for all other cancer patients consistent with other programs that have increased coordination among providers.²⁶

Table 5: Changes in Volume and Receipts for Rural Cancer Outreach Program Patients Seen at MCC

	Pre-RCOP**	Post-RCOP*	Change (%)
All Patients from RCOP Areas Seen at MCC	6958	7572	9%
Cancer Patients from RCOP Areas Seen at MCC	173	743	330%
Estimated Receipts, MCC	\$1,770,256	1,879,542	6.2%
Estimated Receipts, RCOP	NA	\$2,314,516	-
Total Estimated Receipts	\$1,770,256	\$4,194,058	137%
Inpatient Admission, MCC	\$12,268	\$7,370	-40%

*represents average values of 1988 and 1989 financial data

**represents average values of 1992 and 1993 financial data

Similar results of improved clinical care process, equal or better patient outcomes, and cost savings have been reported from the Manitoba Cancer Outreach Program, but final results have not yet been published.^{27;27;28} (and personal communication, Dr. Harvey Schipper, 1998 }

Coordinated Care Models

Coordinated care offers many advantages for terminally ill cancer patients. A randomized clinical trial of a nurse coordinator for terminally ill patients in England did not change any disease outcomes; patients still died, and most still had some unrelieved symptoms, but patient and family satisfaction was helped slightly²⁹. However, the total costs were reduced from £8814 to £4414 for cost savings of 41%^{.26} The savings came from decreased hospital days and a shift to outpatient care, as reported by Bruera et al and Desch et al above. The coordinator did not have any additional resources at his or her disposal, but could compel the physicians to make home visits, and could coordinate the available home services.

Ethics in the ICU

An educational ethics program for surgical staff in the surgical intensive care unit (SICU) directly addressed the issues of patient choice about dying, and the ethics of futile care. This was temporally associated with a decrease in length of stay (LOS) from 28 to 16 days, and a decrease in SICU days from 2,028 to 1,003 days.³⁰ Other units had a decrease in LOS from 9 to only 7 days during the same time period. The cost savings to the hospital were estimated at \$1.8 million. Again, the rapidly changing health care system in Boston could account for some of the change, but more ethically based care that valued the perspective of the patient caused no increased costs, and may have substantially decreased costs. Whether the program can be replicated or sustained, or whether it was dependent on the personnel involved, is not known at this time.

Dowdy and colleagues³¹ at Bon Secours St. Mary's Hospital, in Richmond, Virginia have replicated a similar program in a large community hospital. They assessed the effect of “proactive ethics consultation on patient care communications and on decisions regarding high-risk intensive

care unit (ICU) patients.” They compared three interventions on 99 ICU patients treated with >96 hours of continuous mechanical ventilation. 1) a baseline group enrolled in the study prior to the establishment of the hospital's ethics consultation service; 2) a control group where ethics consultation was at the option of the care team; and c) a treatment group where the ethics service intervened proactively after patients received >96 hrs of continuous mechanical ventilation. For subjects in the proactive group patient care planning was reviewed with physicians and with the care team using a standardized set of prompting questions designed to focus discussion of key decision-making and communication issues. Action strategies were suggested to those in charge of the patient's care. Post discharge chart reviews of the three groups indicated no statistically significant differences on important demographic variables including age, gender, and acuity. Comparisons of the three groups indicated more frequent communications, more frequent decisions to forego life-sustaining treatment, and reduced length of stay in the ICU for the proactive consultation group. The mean ICU LOS for the baseline, control, and proactive groups were 29.4, 25.3, and 18.2 days for those who survived, and 17.3, 21.3, and 14.9 days for those who died. Hospital charges were 16% difference, not statistically different. They concluded that proactive ethics consultation for high-risk patient populations may improve decision-making and communication and reduce length of ICU stay for dying patients.³²

Use of outcomes management

Use of outcomes management (including critical paths, clinical pathways, and the like) for gynecologic surgery and critical pathways for lung, breast, and colorectal cancer all appear to have given improved clinical results with less cost. (These and other studies were reviewed in depth in Clinical Practice Guidelines.)

Length of stay and costs can be reduced for radical prostatectomy.³³ Patient complications and satisfaction do not appear to be worsened.³⁴

Length of stay and costs can be reduced for gynecologic oncology surgery. Patient satisfaction remains high even as length of stay is cut in half.³⁵

Coordinated management of lung, colorectal, and breast cancer patients led to substantial cost savings, mostly from reduced length of stay, with no decrement in care.^{36;37}

Koch et al³⁸ used a collaborative care model of a clinical pathway coordinated by a clinical nurse specialist to improve care for patients undergoing radical retropubic prostatectomy. There were no discernible ill effects. (In addition, pain management was emphasized and standardized.) Mean LOS was reduced from 5.7 to 3.6 days, with total hospital charges reduced from \$13,783 to \$7,741 ($p < 0.0001$).

Koch et al developed a similar program for radical cystectomy and urinary reconstruction³⁹. Hospital LOS decreased from 12.7 to 10.3 days ($p=0.04$), and hospital charges from \$31,174 to \$19,479 ($p > 0.0001$). Savings were distributed in all categories. Blood loss, duration of surgery, and complications were all reduced.

Hospice vs. Non-Hospice Care

The available data cannot answer whether hospice improves care *and* saves money, just saves money, or even improves care.^{40;41} The only randomized controlled trial of hospice vs. standard care is now 15 years old; this study showed no differences in medical outcomes or costs for patients randomized to hospice or standard care.⁴² The shortcomings of the study are several: 1) it was done at a Veterans Administration Medical Center and therefore included mostly male blue-collar workers, not representative of most hospice patients; 2) the hospice unit was newly formed and inexperienced and did not have routine referral lines (which probably would have precluded the study); and 3) the VAMC does not issue bills, so all costs were estimated using costs from nearby hospitals. The intervention was a special inpatient hospice unit with home care services for 247 patients in the trial, done in the period 1979-82, but using accepted hospice philosophy and principles. Hospice did not improve quality of care by any measured benchmark (pain, ability to perform activities of daily living). Patients still used many hospital days, 48 for control, 51 for hospice, but more of the hospice patients were hospitalized on the hospice unit. There was no difference in diagnostic procedures. Total costs of about \$15,000 per patient showed no difference in the treatment groups. This study provides the best evidence that hospice will not have dramatic cost savings.

Other programs

United Health Care's Centers of Excellence program (for BMT and other transplants) has been in operation for several years. One impetus to this program was the demonstration of a threshold effect for safety in bone marrow transplantation; if a center did fewer than 5 procedures a year, the mortality was higher.⁴³ There are no published data on the program.

Salick Cancer Centers have been in operation for nearly 10 years. According to one observer, "They are beautiful structures, beaucoup services (like a psyche consult on all patients), completely avoid the ER—all care given in the clinic 24 hrs a day if needed." There has been no published, peer-reviewed information on the centers.

Individual practices are acknowledged as excellent. For example, Peter Eisenberg's practice in California is guideline-driven, measures outcomes, has prayer services monthly for dying patients, and has the financial structures and expertise to take risk. Again, there is no published peer reviewed data to review.

Monitoring of follow up care

We were unable to find any examples of prospective monitoring of care and improvement of results.

National Cancer Center Network (NCCN)

Significant changes are being made in the delivery of cancer care, at least on paper and in discussions. The important work started by the National Cancer Center Network will provide an attempt to establish all the hallmarks of model cancer programs. However, they are just beginning implementation of the first programs, and evaluation will be several years later.

Summary

The available data show that small sections of cancer care can be improved, with better patient outcomes and often cost control or even savings. Regional palliative and routine cancer care networks have shown modest improvements in outcomes with cost savings. Within single institution pain control, intensive care unit use, and disease management can be improved single with cost savings and preserved or improved quality of care.

However, there are no published data on attempts to systematically improve an entire system of care.

III. Interviews with leaders in the field

Methods

Structured interviews were conducted with opinion leaders to answer the following questions:

1. What are the characteristics of a model of excellence program?
2. What is the BEST cancer program you know? Why? How could it be improved?
3. What should we tell the IOM about models of excellence in practice? Can we define one that IOM can recommend?

These questions were posed to the following group:

1. Gary Lazar, M.D. Medical oncologist formerly with Cedars-Sinai/UCLA, then director of oncology programs for Salick, Inc. Now a nationally respected consultant; current clients include the City of Hope National Medical Center where he is helping design an outcomes management system, and the Advisory Board Co. in Washington, D.C.
2. Gale Katterhagen, M.D. Medical oncologist, leader in the field of integrated managed care. Medical Director, Sutter Health Systems that includes 26 acute care hospitals and 13 medical groups in Northern California.
3. Laura Esserman, M.D., MBA Surgical Oncologist, Director of the Breast Care Center, UCLA.
4. Harvey Schipper, M.D. Director, Manitoba Cancer Research and Treatment Centre, Winnipeg, Manitoba; developed the Manitoba Cancer Outreach Program between Winnipeg and 8 rural communities/hospitals.
5. Eva Grunfeld, M.D.,Dr.Ph. Currently Associate Professor, Kingston, Ontario, affiliated with the National Cancer Institute of Canada office. Primary care specialist with special interest and the major publications about specialist vs. generalist follow up care.
6. Sara Goodlin, M.D. Internist and gerontologist, Faculty Scholar in the Project on Death in America, who is attempting to standardize care in New Hampshire hospice facilities.
7. Henry Burns, Director, Ch.B. Director of Public Health, Greater Glasgow Health Board, Glasgow, Scotland. (1 million people) Surgeon by training, now director of public health; they have made the decision to limit cancer care to those providers who will agree to adhere to evidence based guidelines and submit to national audit. Full results will be available in 1999.

Based on these interviews, the characteristics of models of excellence were summarized in Table 6. Full comments and text of the interview are listed in Appendix I.

Table 6: Interview summary for clinical practice guidelines

Topic	Comments
Characteristics of a models of excellence program	

Physical/structural	<p>General agreement that a full complement of services, from screening to treatment to follow up care, to death, must be available within the health care network. However, this did not need to be in one physical location.</p> <p>In general, as long as there was reasonable access for those with the disabilities associated with cancer, “niceness” of facilities was not perceived to be important.</p> <p>The physical plant should be designed for patient ease and access, not necessarily for health care professional ease.</p>
Personnel	<p>More important than physical location.</p> <p>Multidisciplinary format favored by all respondents; reasons included fewer delays, more limited surgery, and more balanced approach to treatment.</p> <p>Volume, track record, and demonstrable outcomes more important than where one trained.</p> <p>Scotland only permits those who agree to abide by evidence based guidelines, and agree to external review based on a national set of audit criteria.</p>
Patient selection	<p>“Patients define excellence differently....” –from a medical center director and two time cancer survivor.</p> <p>Agreement that patients can drive some systems to better outcomes.</p>
Services/Treatments offered	<p>Agreement that services should be standardized agreed by the staff on a regular basis, and follow guidelines (with some concern that formal guidelines may be too slow.)</p> <p>Agreement on short time from diagnostics to treatment.</p>
Outcomes	<p>Most important part of standardization.</p> <p>Most respondents agreed with a set of outcomes to measure:</p> <ol style="list-style-type: none">1. Clinical: disease free survival, survival, complications, etc.2. Patient: satisfaction, quality of life (no agreement on methods)3. Process of care: compliance with guidelines, etc.4. Costs.
Tracking system for Outcomes	<p>Must have a system for measuring at least 1, 2, and 4 above.</p> <p>Must have some method of feedback to practitioners.</p>

BEST cancer program you know?	Multi-disciplinary: mentions of M. D. Anderson multi-disciplinary clinics, Monica Morrow's program at Northwestern, City of Hope. Cancer Care Ontario is the only province wide program addressing these issues. Agreement that none had reached full potential, in that none were routinely measuring outcomes and improving care.
What should we tell the IOM about models of excellence in practice?	Need <u>Consumer Reports</u> of cancer care. There are some aspects of excellence that are more expensive and time consuming. Patients experience what their needs are, not what the cancer center can provide. Any good cancer center should be able to set performance targets. Agreements by practitioners to abide by evidence based guidelines, and submit results to external scrutiny. The majority mentioned the need for clinical trials both to improve care and improve the process of care.

This group of experts confirmed the findings from the literature review. Like the expert panel from the clinical practice guideline section, all are convinced that processes, outcomes and financial outcomes can be improved.

They are in agreement that a full range of services must be available to patients, but most believe this does not need to be in location or even all within one health care system. All argue for multi-disciplinary group approaches in the clinic.

A uniform part of their approach is the necessity of practitioners to standardize their care, have outcomes tracked, and receive feedback on performance. Scotland has moved ahead to limiting cancer care to those practitioners who will agree to evidence based guidelines, and submit their results to external scrutiny; full results of the first three years of that program will be available in 1999.

V. Summary

There is no single well-tested model of excellence that can be described. The general characteristics of a model of excellence would be include at least the following:

- Coordinated care with one person in charge
- Ease of access
- Ready access to information, answers to questions, and psychosocial support
- Multidisciplinary care with transparency for patients among the disciplines
- Guidelines for patient management of all common problems
- Full range of services from prevention to survivor follow up and hospice care
- Measurement of patient processes and outcomes to ensure good care
- Accountability of health care providers to measured outcomes
- Acceptable pre-determined cost.

Parts of this model can be incorporated into standard types of care and health care systems at present. This could include coordination of care, and agreement of one person in charge. Multidisciplinary programs are becoming more common, but there is as yet no evidence of their superiority to standard care. A full range of services must be available, but they do not need to be under one roof; more important is that care is coordinated within the system.

The primary focus of most demonstration projects has been the cost of care, with the assumption that the quality of care will remain the same or improve; evidence to date suggests that quality is preserved or improved. More work needs to be done on models with the goal of improving care where improvement is most needed.

Essentially all the experience to date has been in expert programs which serve well educated, insured, and high socioeconomic class patients. In addition, the current managed care experience has been from long-established staff –model HMOs which serve the same population and have good if not excellent care. Little is known about how less able programs will perform in coordination or care delivery or disease-management, or how under-served populations will fare under such models. Negative publication bias will almost certainly keep some “failed experiments” from public scrutiny.

A major impediment to fully coordinated care is the current reimbursement system. As long as practitioners are dependent on maintaining income by providing discrete episodes of care, and as long as procedural reimbursement far exceeds evaluation and management reimbursement, change will be slow in coming. Other hindrances to improvement include the necessity of entrepreneurship to make changes in a system that works well for some; the need to learn additional education and psychosocial skills, and the lack of acknowledged limits on health care resources. (As a pharmaceutical representative who sold recombinant erythropoietin told one of use (TJS), “Your perspective is so different. The doc in the office, his only goal is to help the patient in front of him. He doesn’t think it’s his job to save Medicare.”

V. Recommendations

Substantial improvements in cancer care management and cost can be made by incorporation of some of the principles outlined in the Models of Excellence paper. These include:

- Creation of disease management programs to standardize care using predetermined clinical guidelines and pathways.
- Coordination of care, with one person in charge.
- Accountability for outcomes, with approved methods of care and feedback on performance.

While no single or simple model of excellence can be made, there is general agreement on the type of care desired. This model would require major change in some organizations to incorporate ease of access, accountability for performance, agreement to auditing, standardized care, written treatment plans, etc. There are practices that embody these principles, but there is no published information on their results except for specific disease situations. The model of excellence would not be restricted to any particular type of payment system, e.g. fee for service or staff model health maintenance organization, but may be hard to accomplish with multiple independent practitioners.

The current system of reimbursement constitutes a significant barrier to improving care. Impediments include 1) separate reimbursement for each specialist; 2) high reimbursement for technical procedures (surgery, chemotherapy administration, and radiation planning and treatment charges) and commodity sales (chemotherapy); and 3) low reimbursement for coordination of care, and evaluation/management, especially outside of the traditional office visit. Solutions will almost certainly require a single health care professional in charge and accountable, and either disease management reimbursement (in a capitated system), or pre-determined revenue sharing based on work done (in a fee for service system).

Characteristics of a Model of Excellence Program

T. Smith MD

Interview	Date	Physical/Structural	Personnel	Patient Selection	Services/Treatments Offered	Outcomes	Tracking System for Outcomes	Best Cancer Program	Tell the IOM
Burns, Harry MB. Director of Public Health, Glasgow, Scotland. (1 million people) Surgeon	18 May	Not important.	Some of the best technical surgeons were working in out of the way hospitals. The teaching hospital clinician is not necessarily the best guy to take your colon out.	Socioeconomic deprivation important in adjusting case mix. 10% difference in survival based on this alone. Differences larger for other cancer. I.e. lymphoma. Robust system for measurement.	Mixed economy of services for hospice care. All services available.	Will have outcome data for first 3 years of program next year. Have noted 9% difference in survival at 5 years, 5% at 10 years at multidisciplinary clinics for breast cancer. Adequacy of primary surgery seems to be good predictor of long term survival. Track survival, process, complications	Full audit set for all clinicians doing cancer work. All must agree to follow guidelines, allow access to care for core audit sets.	Any clinician can treat cancer as long as he is prepared to adhere broadly to evidence based guidelines and – crucially – so long as he is prepared to submit his results to external scrutiny.	Guidelines are agreed by the clinicians working as a group. External scrutiny and accountability are essential parts of the system. Better overall survival is the prime target.
Schipper, Harvey	26-May	First, established that societal perspective was to be used. These characteristics are basically not important or are of diminished importance. There must be some piece of early diagnosis, education, directed screening especially for those at high risk.	Once in, should be evaluated quickly in multi-D setting. Multi-D gives fewer delays, more limited surgery, more balanced approach to treatment. No hard proof of that, yet. Blocks should be built for patients, not staff or hospital. Should be information-	Not sure what was meant by the question.	Should be "de facto" standardized. Clinical practice guidelines may be too slow. The group of multi-D staff should standardize the approach to common patients, modify as needed when new information comes available. Must be full service from prevention to	Should be linked to registry, surveillance system. Process - time of visit, RVU's, convenience, trajectory of patient, quality of life - all important.	Main outcomes: 1. OS/DFS. 2. QOL. 3. Process track - delay, tests done, GIVIO study, online registry. 4. "are you satisfied" How much time did you spend?" may be as important as anything else.	M. D. Anderson model of multi-D clinics. Must extend to community practice, beyond the walls of the center.	Consumer reports of cancer care. Not big brother - just controlling quality.

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Esserman, Laura	5/27/1998, June 2	One physical location where all resources are easily navigated.	Sufficient personnel to allow staff not to be stressed. Multi-D: nurse practitioners, surgeons, radiologists, oncologists, all familiar with all aspects of breast cancer care.	All patients with breast cancer, breast abnormality or cancer. All stages and types of cancer.	Comprehensive. From screening to treatment to hospice. Short distance and time to diagnostics and work up. Ability to compare treatments based on process measures and outcomes, incl patient satisfaction.	Ability to compare outcomes at all stages, based on process, outcomes, patient satisfaction. Outcomes must include more than mortality. Rates of lymphedema, neuropathic pain, cardiac toxicity from chemotherapy, BMT morbidities, cancer found to be biopsy p	Determine outcomes of importance to patients, back into the process and outcome measures that will predict outcomes. Determine primary data elements, capture information at point of care, and diagnosis. Routinely provide data from your center and nation	Van Nuys had it all: multi-D, one roof, common standards, expert care. ["Salick ruined it all."] Monica Morrows program at Northwestern has potential for same reasons. Current program has potential, but is a year away from optimal.	As cancer care becomes more complex, with more treatments with marginal differences, communication issues and education become even more critical. There are some aspects to excellence that are expensive, more time consuming (education and personnel time)
Grunfeld, Eva	27-May	Without walls. Non sectional. Centralize services only if evidence base or practical such as radiation. Need to maintain quality of care.	What is needed by patients, not what is available.	Population based, not limited to needs.	No specific models "excellent" but tailored to needs of the pt not what can be provided. tailor services esp supportive care, psychosocial. Needs service pathway of needs, services, evidence. Can work just as well if docs or non docs but must be evidence b	Disease specific, population based. Stage at diagnosis. Socioeconomic status for adjustments.	Million problematic issues. Need to have all institutions providing data and uniform set of reporting requirements. Importance of QOL as outcome. As more and more care devolved to community, need to measure care there. The person who gets excellent care f	Cancer Care Ontario is addressing these issues in population based way.	Disagree with first premise: excluding primary care. Must be population based, must be entire community. Don't segregate prevention, control, from treatment. Patient experience is what their needs are, not what the center provides or just prevention. At

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Katterhagen, Gale Medical Director of Sutter Health, 26 Hospitals, 13 Medical groups in Northern California	29-May	"So few objective good models" One of our undoings has been dependence on structure. Too much time, \$ on physical plants. None so far designed for patient or provider convenience, ease of use.	Most important. From subjective to objective, most important. Excellence in MDs drives the system. Can happen if MDs are good, but not if MDs are bad. No one else can make the system perform well.	They define quality of care differently than we do. (He is a 2-time cancer survivor.) Pushing excellence in the system provides good satisfaction. Patient satisfaction scores not useful or reliable: need to ask patients what they would change, give their	Mandatory: multidisciplinary. Must have docs in the same room. Support (RN, MD, Pastoral care, radiology, etc.) Whole spectrum of cancer care from hospice/cure/berea vement. "Now, that's a real cancer program." If in hospice, good pain/s	3 classes of outcomes: Physical - overall survival, disease free survival, SF-36 or other measure of function. Service - access, satisfaction. Costs.	Much ballyhoo over processes. Most information systems "just stink" and cannot track "I" in IS. Most systems cannot pull up OS, DFS, toxicity complications, and costs. Should be able to set performance standards: with 1560 targeted DCIS breast cancer patients		
Goodlin, Sara	3-Jun	Easy access for disabled and not. Hotel comforts. Bright, well-lit, well ventilated educational and clinical research collection space. Dividable space.	Roles, rather than specific personnel. Oncologist (any type) involved along with PCP. Psychosocial support, often not MD. Someone dedicated to education especially about choices of care. Coordinator of care, whom dependent on personalities and styles; some	types of patients drive the type of care, somewhat. Elderly patients or those with comorbidities may choose or be steered to different less aggressive care. Unknown if this is correct.	Cancer center should have at least a liaison with primary care services and prevention ("these belong to PCP, I agree" but PCP can benefit from expertise of cancer center.	Four domains, all important. 1. Clinical outcomes such as OS, DFS, toxicity, symptoms (Pain, Fatigue). Disease and treatment specific. 2. Functional status, by patient report not MD report (Dartmouth COOP model.) 3. Satisfaction of patient and family. "	Measure 1-4 above. Use waiting room to gather performance/function data.	None.	Outcomes must be tracked in a number of domains, not just one. Clinical and other data equally important. Patient and family needs and requested services vs. what the center is willing to provide. Openness to improvement - monitor processes and outcomes

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Lazar, Gary	9-Jun	Important but not that important.	As important as any service business. Choice of caregivers critical: how to pick problematic. Volume and outcomes. Track record, Interest in clinical trials. Where they trained not important. RN - experience in all phases of care, home to IP.	Full spectrum not necessary as long as available. pCP control of screening and prevention. Full spectrum of diagnostic services can be marketing, not service or outcome based.	Single most important point: must be tracked and must be comparable across centers. 1. Clinical. Appropriateness. Compliance with cpgs. Os/dfs/morbidity [who can name, now?] 2. Patient. Satisfaction. Qol 3. Processes. Hedis. Access not an issue in U.S. % in hospice. 4. cost.	Relational database of 1-4. Outcomes across the systems. Pt level data entered in office.	city of hope? Some very good ones, no great ones. The good ones 1. Measure outcomes, #1. 2. Decide what they want. Primary care. Tertiary care. Compete. Collaborate.	highest quality is achievable but requires documentation. Convenient. Compassionate. Full spectrum of services available to patients. Clinical trials important to both docs and patients with this disease. Alternative treatments needed. Every oncologist believes they are providing the very best care available.
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