Cancer As Chronic Disease

Shared Themes,
- Unique Challenges

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Case Study

A 38 y.o. woman with stage 4 breast cancer is told to “put her affairs in order” and “say her goodbyes”

As she prepares for her death she is tested for presence of a specific mutation.

She tests positive

She starts a new drug

She tells this story, 10 years later, to Lance Armstrong, Elizabeth Edwards, and Ted Koppel
Case Study

The test was HER2/neu
The drug was trastuzumab (Herceptin)
She has had multiple recurrences and multiple courses of Herceptin
Case Study : The Flip Side

Many women with HER2 negative breast cancers are receiving Herceptin

It doesn’t work
Projected US Cancer Incidence
All Sites (2000 – 2050)

1.3 Million
2000

2.6 Million
2050

100% Increase
5-Year Relative Survival Rates – Trends
All Races (1974 - 2000)

Mid-1950s: 35%
1974-76: 50%
1995-2000: 64%
Number of Cancer Survivors in US: 1971 to 2002

Data source: 2004 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2002 were based on the average of the July 2001 and July 2002 population estimates from the U.S. Bureau of Census.
Projected U.S. Cancer Prevalence
All Sites (2001 – 2030)

- 9.2 Million (2001)
- 18.5 Million (2030)

100% Increase
We Will Discuss:

Is cancer a chronic disease?
What features does cancer share with other diseases?
What features of cancer are unique?
What challenges is cancer creating for the U.S.?
What disease management strategies will work?
What will it take to solve the cancer problem?
Can “solving” cancer dilemmas guide us to broader solutions?
Cancer is a chronic disease
Cancer As Chronic Disease

• It lasts for over 3 months
• It’s impact is long-lasting – even for patients who are “cured”
• Cancer impacts quality of life, cost, health care utilization, morbidity, and mortality
Like other chronic diseases, cancer . . .
“can be disabling, cause intense pain, cause embarrassment and be stigmatizing.”

ACS “Studies of Cancer Survivors”

In response, The Behavioral Research Center of the American Cancer Society has implemented a program of research to assess the quality of life and psychosocial functioning of cancer survivors.

Program includes three major research studies:

- Study of Cancer Survivors-I (SCS-I)
- Study of Cancer Survivors-II (SCS-II)
- Study of Cancer Survivors-Caregiver
## Medical Characteristics (n = 13,334)*

<table>
<thead>
<tr>
<th>Time Since Diagnosis</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Year</td>
<td>32</td>
<td>4,229</td>
</tr>
<tr>
<td>3 Years</td>
<td>24</td>
<td>3,177</td>
</tr>
<tr>
<td>6 Years</td>
<td>24</td>
<td>3,257</td>
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<tr>
<td>11 Years</td>
<td>20</td>
<td>2,671</td>
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</table>

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>%</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>32</td>
<td>4,252</td>
</tr>
<tr>
<td>Prostate</td>
<td>25</td>
<td>3,300</td>
</tr>
<tr>
<td>Colorectal</td>
<td>21</td>
<td>2,822</td>
</tr>
<tr>
<td>Skin Melanoma</td>
<td>8</td>
<td>1,083</td>
</tr>
<tr>
<td>Uterine</td>
<td>8</td>
<td>1,043</td>
</tr>
<tr>
<td>Bladder</td>
<td>6</td>
<td>834</td>
</tr>
</tbody>
</table>

*represents only survivors of the 6 cancers including in both SCS-I and SCS-II
Comparison of Mean SF-36 Score by Time Since Diagnosis

Population Mean = 50

SCS combined dataset (n=13,334). Scores adjusted for race, co-morbid conditions, and age.
Comparison of Mood Disturbance (POMS) by Time Since Diagnosis

SCS combined dataset (n=13,334). Scores adjusted for race, co-morbid conditions, and age.
"Top Five" Cancer-Related Problems

SCS combined dataset (n=13,334). Cancer Problems in Living Scale (CPILS).
Analysis Summary

- QoL deficits are most prevalent and distressing among 1-year survivors

- However, some problems do persist among moderate and long-term survivors

- Two major “themes” have emerged:
  1) cancer-specific distress
  2) fatigue and sleep disturbance

- Findings are PRELIMINARY; additional analyses will take other factors (cancer type, treatment, recurrence, etc) into account
Cancer Shares Important Features With Diabetes And Heart Disease

- Lifestyle, genetics, and environment impact risk of disease development
  - Some of these risks are modifiable
  - Many of the same factors impact risk for all three diseases
Chronic Disease: Shared Features

• Precursor Conditions Exist
  – Some precursor conditions are detectable and modifiable
  • Pre-diabetes
  • Pre-hypertension
  • Pre-cancer
    – Colon polyps
    – Cervical dysplasia
    – Ductal carcinoma in situ
Chronic Disease: Shared Features

• Generally speaking, earlier diagnosis contributes to superior outcomes
  – True for diabetes, hypertension, hyperlipidemia, CHF
  – For most solid tumors, survival time is determined by stage
    • Cure potential greater with earlier stage
How effective are cancer prevention and early detection strategies?
What Does “Early Diagnosis” Of Cancer Mean?

• What we call “early diagnosis” may not be truly early
  — Lead-time bias
    • Survival vs. mortality

• But most cancers may have a stage or timing threshold
  — Proteomics, genetic markers, molecular imaging may usher in a new era of truly early detection
As for most chronic disease, prevention and early intervention yield greater health benefit than treatment of symptomatic disease.
Chronic Disease: Shared Features

- Treatment effectiveness determined by multiple factors
  - Access to care
  - Timeliness of care
  - Availability and adherence to evidence
  - Clinician recommendation
  - Patient adherence
Determinants Of Treatment Effectiveness For Chronic Illness

• Prognosis correlates with
  – Insurance status
  – Income
  – Education level
  – Racial/ethnic factors
  – Social support
Disease Management: Navigation From Screening Through Treatment

Navigation is associated with:

- Improved rate of screening and follow-up
- Lower clinical stage of presentation
- Higher patient satisfaction
- Improved patient tracking and support
- Improved communication and trust with disadvantaged populations

Dohan D; Shrag D Cancer 104 p.1-8 2005
Harlem Hospital Breast Cancer Patient Navigation Program

- Reduced screening gap
- But no closing of mortality gap
- Methods:
  - Historical comparison of breast cancer mortality
# Harlem Hospital Breast Cancer Patient Navigation Program: Results

<table>
<thead>
<tr>
<th></th>
<th>1964 to 1986 (N=)</th>
<th>1995-2000 (N=X w/ PN)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early stage</td>
<td>6%</td>
<td>41%</td>
</tr>
<tr>
<td>Late stage</td>
<td>50%</td>
<td>21%</td>
</tr>
<tr>
<td>Survival</td>
<td>39%</td>
<td>70%</td>
</tr>
</tbody>
</table>
But . . . .

Cancer is different from heart disease and diabetes in important ways
Cancer As Chronic Disease: How It’s Different

• Cancer is a policy and political “untouchable”
• Cancer is, actually, many different diseases
• Many people are cured
  — Largely seen as a “win or lose” proposition
• Costs are front-loaded in the first two years after diagnosis
• Cancer treatment has intermittent spikes and long dormant periods
• Changes outlook on life
How Cancer Differs: The War Analogy

• The cancer battle is fought by heroes who triumph or bravely succumb

• Diabetes is an annoyance that wears you down and makes you feel guilty about less than perfect lifestyle choices and results
Implication Of The Cancer War Analogy

• More dollars in research and care
  — Greater public advocacy
• Greater political power and clout
• Creation of “untouchable” status for cost-control efforts
Cancer’s Untouchable Status

- “Any willing drug” mandates
- Insurance company’s are VERY reluctant to apply evidence standards to coverage decisions for cancer
  - And multiple evidence gaps exist
  - Off-label uses are rampant . . . and, often, reasonable
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Patients Often Don’t See Cancer As A Chronic Disease

• The concept of cancer as a chronic disease is new.
• Focus groups conducted by Julie Becker, PhD
  — Many breast cancer patients don’t buy the concept
  — Patients with stage IV breast cancer see it as a violent battle
  — The newer therapies are better tolerated – improved quality of life
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Costs Come Early:

- Despite new medicines, the bulk of costs are generated early on
  - Surgical resection
  - Radiation
  - Hospitalizations
- A second spike occurs towards end of life
- The new medicines and therapies are contributing to higher costs and longer into illness
Sequelae Of Front-Loaded Costs

• Co-pays and deductibles may be very high
• Even well-insured patients have high out of pocket expenses generated over a short period
• Limits access to care and impacts quality of life
Consequences of Financial Costs of Cancer by Insurance Status

Percent who say each of the following happened to them/their family member as a result of the financial cost of dealing with cancer...

- **Used up all or most of savings**: Ever uninsured 46%, Always insured 22%
- **Borrowed money from relatives**: Ever uninsured 30%, Always insured 10%
- **Contacted by a collection agency**: Ever uninsured 34%, Always insured 9%
- **Unable to pay for basic necessities like food, heat, or housing**: Ever uninsured 41%, Always insured 7%
- **Sought the aid of charity or public assistance**: Ever uninsured 35%, Always insured 7%
- **Borrowed money/got a loan/another mortgage**: Ever uninsured 15%, Always insured 6%
- **Declared bankruptcy**: Ever uninsured 6%, Always insured 3%

Source: USA Today/Kaiser Family Foundation/Harvard School of Public Health Cancer Survey (conducted August 1 – September 14, 2006)
Understanding The Costs Of Cancer Care

• 2005 total cost: $209.9 billion
  — $74 billion in direct medical care
  — $17.5 million in indirect morbidity cost
  • Lost productivity
  — $118.4 billion in indirect mortality cost
  • Lost productivity due to premature death

ACS: Cancer Facts and Figures 2006
## Costs Of Colorectal Cancer Treatment

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Cost per 6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>FU/LV for 5 days monthly</td>
<td>96</td>
</tr>
<tr>
<td>Infusional FU/LV every 2 weeks</td>
<td>352</td>
</tr>
<tr>
<td>Capecitabine for 14 days, every 3 weeks</td>
<td>11,648</td>
</tr>
<tr>
<td>Irinotecan every 3 weeks</td>
<td>30,100</td>
</tr>
<tr>
<td>Bevacizumab (alone) every 2 weeks</td>
<td>23,897</td>
</tr>
<tr>
<td>Cetuximab (alone) weekly</td>
<td>52,131</td>
</tr>
</tbody>
</table>

Meropol NJ; Shulman KA J Clin Oncol 25(2) 180-186 Jan, 2007
Colorectal Cancer Treatment: Cost-Benefit

The aggregate drug cost for treatment of patients with colorectal cancer is $150,000 to $200,000 for an additional year of survival compared with FU/LV.

But what does “an additional year of survival” mean?

It means a few individuals survived for many years, and a few did not benefit at all.
Cancer Care – Can The Free Market Handle This?

• Spending as consumer choice

• When consumers believe the volume is worth the cost, they spend on that product or service
But Health Care Spending Is Different

- Health care insurance dramatically lowers the consumer piece of the pie
  - Moral hazard
- Consumer and Physician impact cost through choice of therapy and imaging
- Behavioral economics
  - Desperate people make riskier choices
  - Prospect theory

Gaskin JD et.al. Med Decis Making 25:609-613 2005
Is Cancer The Cause Of Spiraling Health Care Costs?

• Despite the high cost (approximately $100 billion) of cancer care, it accounts for only 5% of the $1.9 trillion spent in medical care
  — Rate of growth paralleling overall growth of medical care
  — (The hidden cost of worried well testing may be underestimated)

• Slowing expenditures on cancer care will not solve the crisis in health care costs

• So why worry about it?

We Need To Worry About Cancer Care Costs

- Excess treatment causes harm
  - False hope
  - Financial impact on survivors
  - Reduction in quality of life
  - Morbidity and premature mortality for some
  - Competition for cancer dollars
Cancer Cost Trade-Offs

• Very expensive care to add months of life is often unchallenged and is covered by insurance

• Coverage for prevention is rigorously scrutinized and often requires state or federal mandates (denominator of eligible individuals is much greater)

• Expense of new therapies is changing the financial proposition
Implication Of Oncology Coverage

Case Study:
45 y.o. woman, one of 7 employees in a small company, had metastatic breast cancer.

Jan-March: Herceptin
April-May: Herceptin & Vinorelbine
June-Aug: Herceptin & Gemcitabine
Aug-Dec: Herceptin, Gemcitabine & Bevacizumab
Claims for 2005: $148,615

Case Study:
Appeal for coverage was successful!
Case Study: Conclusion

• Company’s premiums went up

• Employer terminated insurance benefit
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“I am a diabetic”

“I have cancer”
Cancer is a pollution of the body; an invader; an enemy

Patients fight to kill it, expel it, to defeat the foreign agent
The moment patients receive a cancer diagnosis, death becomes more real. They feel that threat, even if it is small.

Many without cancer fear it. This fear is an important driver of health care utilization and testing.
“Having cancer was the greatest lesson about life I’ve ever had. I’ve learned more about my family and my friends and about good and bad relationships. I’ve learned what’s important and what’s not. I’ve learned how to treasure life. Nothing has ever taught me more…..And I’d trade it all back in a heartbeat”
Cancer creates passion and passion creates volunteers who start organizations. The not for profit cancer organization industry is a multi-billion dollar engine
Confronting Cancer In The U.S.: Putting It All Together

• Investment in evidence-based prevention and early detection is vital
• Primary care must be expanded
• Access to prevention and cancer care must be provided for all
• Trials that assess value of treatment options are critical
• Treatment based on evidence must be paid for
Putting It All Together

• All chronic disease should be considered fairly
  — Preferential payment for cancer care over heart care is not sensible
Treatment

- Care for potentially curable diseases should be provided for all
- Therapy that significantly prolongs life should be provided for all
- Payment for therapies where cost significantly exceed cost-effectiveness thresholds should require a higher insurance premium or greater out of pocket spending
Case Study

L.S. had colon cancer found at routine colonoscopy 4 years ago.
Brain, lung and spine metastases appeared 4 years later.
Multiple courses of chemotherapy became increasingly ineffective.
He started to consider stopping treatment.
Case Study

Radiotherapy eliminated brain and spinal metastases.
Lung metastases were treated with needle guided radiotherapy ablation
- He was the third person to receive this therapy
9 months after considering ending treatment, he has no detectable evidence of cancer
Putting it all together

• Improved strategies for communicating risk and benefit of non-curative therapy are needed

• Decisions to forgo non-curative therapy should be supported, including provision of high quality end of life care
  — Lessen the stigma of stopping treatment
Solving the cancer problem will not solve the health care crisis . . . but it can illuminate the road
If the nation can embrace a national approach to cancer care, we, very possibly, can do it for all care
Case Study

A man in his mid 20’s developed cancer that was metastatic to lungs and brain. He underwent grueling chemotherapy. Today, 10 years later, he considers having cancer to be the greatest thing to ever happen to him.
Even greater than winning the Tour de France 7 times