The Origin and Evolution of Patient Navigation

Georgia Patient Navigation Society Meeting

July 26, 2009
Atlanta, GA

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Founder and President of Ralph Lauren Cancer Center
Senior Advisor to the Director, The National Cancer Institute
Significant medical advances have improved health and quality of life for many Americans.
The poor and underserved have not shared fully in these benefits, as evidenced by their high cancer incidence, mortality, and lower survival.
Poor Americans have a 10 to 15 % lower cancer survival rate compared to other Americans.

American Cancer Society Report on Cancer in the Economically Disadvantaged 1986
Life Expectancy at Birth – USA
(CDC/National Center for Health Statistics Report 2006)

Figure 2. Life expectancy by race and sex: United States, 1970–2003

- White female
- Black female
- White male
- Black male
Cancer Incidence Rates* by Race and Ethnicity, 1999-2003

Rate Per 100,000

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Men</th>
<th>Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>555.0</td>
<td>421.1</td>
</tr>
<tr>
<td>African American</td>
<td>639.8</td>
<td>383.8</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>385.5</td>
<td>303.3</td>
</tr>
<tr>
<td>American Indian/Alaska Native</td>
<td>359.9</td>
<td>305.0</td>
</tr>
<tr>
<td>Hispanic†</td>
<td>444.1</td>
<td>327.2</td>
</tr>
</tbody>
</table>

*Age-adjusted to the 2000 US standard population.
†Person of Hispanic origin may be of any race.


Rate Per 100,000

*Per 100,000, age-adjusted to the 2000 US standard population.
† Hispanic is not mutually exclusive from whites, African Americans, Asian/Pacific Islanders, and American Indians.
Figure 6.3. SEER Cancer (All Sites Combined) Survival Among Men, 1988–1994 Patient Cohort

Percent of Census Tract Population Below Poverty Level in 1990

- < 10%
- 10% to 19.99%
- 20% or higher

<table>
<thead>
<tr>
<th></th>
<th>&lt; 10%</th>
<th>10% to 19.99%</th>
<th>20% or higher</th>
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</thead>
<tbody>
<tr>
<td>All Races</td>
<td>61.0</td>
<td>55.0</td>
<td>49.0</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>61.5</td>
<td>56.0</td>
<td>51.7</td>
</tr>
<tr>
<td>Black</td>
<td>57.5</td>
<td>51.2</td>
<td>45.3</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>54.9</td>
<td>47.9</td>
<td>43.7</td>
</tr>
<tr>
<td>Hispanic</td>
<td>59.9</td>
<td>55.4</td>
<td>53.8</td>
</tr>
</tbody>
</table>
Figure 6.4. SEER Cancer (All Sites Combined) Survival Among Women, 1988–1994 Patient Cohort

Percent of Census Tract Population Below Poverty Level in 1990

- Blue: < 10%
- Green: 10% to 19.99%
- Red: 20% or higher

<table>
<thead>
<tr>
<th></th>
<th>5-Year Cause-Specific Survival Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Races</td>
<td>63.4 (58.2)</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>63.3 (56.4)</td>
</tr>
<tr>
<td>Black</td>
<td>58.5 (54.5)</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>65.8 (60.7)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>64.7 (60.8)</td>
</tr>
</tbody>
</table>

Note: Based on data from 11 SEER registries. See “Data and Methods” for a list of SEER registries.
The Discovery-Delivery Disconnect

This *discovery to delivery* “disconnect” is a key determinant of the unequal burden of cancer.

*Voices of a Broken System: Real People, Real Problems*, President’s Cancer Panel, Freeman, March 2002
Causes of Health Disparities

Poverty/
Low Economic
Status

Social Injustice

Culture

Possible Influence on Gene Environment Interaction

Prevention  Early Detection  Diagnosis/Incidence  Treatment  Post Treatment/Quality of Life  Survival and Mortality

Freeman, Adapted from Cancer Epidemiology Biomarkers & Prevention, April 2003
<table>
<thead>
<tr>
<th>Poverty</th>
<th>Culture</th>
<th>Decreased Survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inadequate physical and social environment</td>
<td>Inadequate information and knowledge</td>
<td>Risk-promoting lifestyle, attitude, behavior</td>
</tr>
</tbody>
</table>

Freeman, H.P., Cancer in the socioeconomically disadvantaged. Cancer 1989
Geographic Areas of Excess Cancer Mortality
An Analysis of Excess Cervical Cancer Mortality – A Marker for Low Access to Health Care in Poor Communities
Patient Navigation

Historical Time Table

- 1989 National Hearings on Cancer in the Poor
- 1990 Excess Mortality in Harlem, *NEJM* 1990 McCord and Freeman HP
- 1990 Patient Navigator Program Initiated at Harlem Hospital
Patient Navigation

Historical Time Table

- 2004 National Cancer Institute funded 9 Patient Navigator Sites
- 2005 Patient Navigator Outreach and Chronic Disease Prevention Act
- 2006 Center for Medicare and Medicaid Funded 6 Patient Navigator Sites
- 2008 Health Resources and Services Administration Grants – (Patient Navigator Act)
Report to the Nation on Cancer and the Poor

In 1989, as President of the American Cancer Society, I conducted a series of hearings throughout the country to hear the testimony of poor Americans who had been diagnosed with cancer.
Report to the Nation on Cancer and the Poor, 1989

Findings

- Poor people meet significant barriers when they attempt to seek diagnosis and treatment of cancer.
- Poor people often do not even seek care if they cannot pay for it.
- Poor people experience more pain, suffering, and death because of late stage disease.
Fatalism about cancer is prevalent among the poor and prevents them from seeking care.

Poor people and their families must make extraordinary and personal sacrifices to obtain and pay for care.

Current cancer education programs are culturally insensitive and irrelevant to many poor people.
Related to these findings, the first “Patient Navigation” program was conceived and initiated in 1990 at Harlem Hospital Center. Supported by a grant from the American Cancer Society.
Patient Navigation
There is a critical window of opportunity to save lives from cancer between the point of an initial suspicious finding and the resolution of the finding by further diagnosis and treatment.
Central Harlem
Community Characteristics

- Ethnicity is predominantly African-American.
- Median household income in Central Harlem is $22,367/year.
- Median years of school completed is 12.
  - 11% less than high school
  - 47% high school, no diploma
  - 17% high school graduate
  - 18% some college
  - 8% 4+ yrs. of college

Source: National Cancer Institute INFORUM database
East Harlem Community Characteristics

• **Ethnicity**
  - Puerto Rican, 51.8%
  - Mexican, 9%
  - Dominican, 5%
  - Central American, 3%
  - Ecuadorian, 1%

• **Median household income in East Harlem is $23,309/year.**

• **Median years of school completed is 11.**
  - 30% less than high school
  - 31% high school, no diploma
  - 22% high school graduate
  - 13% some college
  - 5% 4+ yrs. of college

*Source: National Cancer Institute INFORUM database*
PRINCIPAL BARRIERS
TO HEALTH CARE

- Financial
- Communication
- Health Care System Barriers
- Fear and Distrust
The Patient Navigator Model promotes timely diagnosis and treatment and aims to ensure seamless, coordinated care and services.

Patient navigators provide assistance to patients and families to “negotiate” the health care delivery system.
Patient Navigation represents a community-based support program designed to eliminate barriers to early diagnosis and treatment of cancer.

It is based on the concept that people in communities trained as patient navigators can be effective in reducing and eliminating barriers to the timely diagnosis and treatment of cancer in their own communities.
# Impact of Harlem Hospital Center Breast Cancer Screening Program

## Stage of Disease

<table>
<thead>
<tr>
<th>Stage</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 0</td>
<td>0%</td>
</tr>
<tr>
<td>Stage I</td>
<td>6%</td>
</tr>
<tr>
<td>Stage II</td>
<td>45%</td>
</tr>
<tr>
<td>Stage III</td>
<td>39%</td>
</tr>
<tr>
<td>Stage IV</td>
<td>10%</td>
</tr>
</tbody>
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Impact of Screening & Patient Navigation on Breast Cancer 5-year Survival Rates
Harlem Hospital Cancer Control Center (BECH)

Before access to screening & patient navigation (1964-1986)*

### Impact of Harlem Hospital Center Breast Cancer Screening Program

Comparison of Five-year Survival Rates (%)

<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>Stage 0</td>
<td>0%</td>
<td>12%</td>
</tr>
<tr>
<td>Stage I</td>
<td>6%</td>
<td>29%</td>
</tr>
<tr>
<td>Stage II</td>
<td>45%</td>
<td>38%</td>
</tr>
<tr>
<td>Stage III</td>
<td>39%</td>
<td>14%</td>
</tr>
<tr>
<td>Stage IV</td>
<td>10%</td>
<td>7%</td>
</tr>
</tbody>
</table>

Oluwale/Freeman, Journal of American College of Surgeons, 2003
Impact of Screening & Patient Navigation on Breast Cancer 5-year Survival Rates
Harlem Hospital Cancer Control Center (BECH)

Before access to screening & patient navigation (1964-1986)*


Oluwale/Freeman, Journal of American College of Surgeons, 2003
Patient Navigation Across The Health Care Continuum

Outreach

Abnormal Finding

Initial target in Harlem Model

Abnormal Results → Diagnosis → Treatment

Resolution

Rehabilitation

Prevention

Early Detection

Diagnosis/Incidence

Treatment

Post Treatment/Quality of Life

Survival and Mortality

Freeman, 2006.
Map of Harold P. Freeman Patient Navigation Institute Alumni

* 247 Alumni to date
150 Healthcare Sites
36 States

Number of Institutions per state: Alabama (1), Alaska (1), Arizona (1), Arkansas (3), California (13), Colorado (1), Connecticut (19), Delaware (1), Florida (4), Georgia (5), Hawaii (5), Illinois (4), Indiana (2), Kansas (2), Kentucky (6), Louisiana (2), New Jersey (4), Maine (1), Maryland (1), Massachusetts (2), Missouri (1), New Hampshire (1), New Mexico (1), New York (28), North Carolina (5), Ohio (1), Oregon (1), Pennsylvania (5), Rhode Island (2), South Carolina (2), South Dakota (1), Tennessee (4), Texas (10), Virginia (1), Washington (1), Washington DC (5)
St. Thomas VI (1), Bucharest, Romania (1)
Ralph Lauren Center for Cancer Care & Prevention PN Model

• Outreach: The outreach navigator is responsible for creating access to the Center. This individual utilizes remote access technology to create real time appointments in the scheduling management system and tracks potential patients through their scheduled appointment.

• Financial: The financial navigator is responsible for removing any financial barriers or obstacles that present amongst the Centers patient population.

• Diagnostic: The diagnostic navigator is responsible for tracking and barrier removal for patients with a suspicious finding.

• Treatment: The treatment navigator is responsible for tracking and barrier removal for patients undergoing treatment services at the Center.
Three Major Factors to Improve Results

1) Provide screening to patients regardless of ability to pay
2) Establish patient navigation program
3) Increase outreach and public education
Signed into law
June 29, 2005
"Patient Navigator Outreach and Chronic Disease Prevention Act of 2005"
P.L. 109-18
Patient Navigation Review of the Literature

- 45 Articles identified (through Oct, 2007)
  - 16 Studies provided data on efficacy of navigation
- Overall, There was evidence of some degree of efficacy
  - Increased Screening 11% - 17%
  - Adherence to diagnostic follow-up care 21% - 29%

Cancer October 15, 2008: Patient Navigation State of the Art or is it Science Well and Others
Patient Navigation Program

- NCI Patient Navigation Program: 9 sites
- NCI Navigator Academy for Clinical Trials
- CMS Patient Navigation Program: 6 sites
- Health Resources and Services Administration Grants: 6 sites (Patient Navigator Act)
Patient Navigation Program

- American Cancer Society Patient Navigator Program: 150 sites
- Susan Komen Foundation Patient Navigator Grant Program ($16 million/annually)
- Avon Foundation: 60 sites
- Pfizer Foundation: 6 sites
No person in America with a suspicious finding or cancer should go untreated.

No person in America should experience delays in diagnosis and treatment that jeopardize survival.

No person in America should be bankrupted by a diagnosis of cancer.
A New Paradigm

Freeman, HP, 2005
The unequal burden of disease in our society is a challenge to science and a moral dilemma for our nation.