The Origin, Evolution & Principles of Patient Navigation

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The “War on Cancer”

Signing of the National Cancer Act of 1971
The Discovery-Delivery Disconnect

Discovery ——— Delivery

Critical 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, September 2001
Access to information and knowledge and Access to quality care

Delivery

Critical Disconnect

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

Freeman, H.P., 2006

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Disease always occurs within a context of human circumstances.

These human circumstances are determinants of survival and quality of life.
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.
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

Years of age

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
POVERTY

CULTURE

Inadequate physical and social environment
Inadequate information and knowledge
Risk-promoting lifestyle, attitude, behavior
Diminished access to health care

DECREASED SURVIVAL
Poverty Rates by Race and Hispanic Origin:
2 Years 2011 and 2012

<table>
<thead>
<tr>
<th>Race</th>
<th>2011</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>9.8</td>
<td>9.7</td>
</tr>
<tr>
<td>Black</td>
<td>27.6</td>
<td>27.2</td>
</tr>
<tr>
<td>Hispanic</td>
<td>25.3</td>
<td>25.6</td>
</tr>
</tbody>
</table>

Percent of People Without Health Insurance Coverage by Race and Hispanic Origin Percentages for 2011 and 2012

- **White**
  - 2011: 14.9%
  - 2012: 14.7%

- **Black**
  - 2011: 19.5%
  - 2012: 19.0%

- **Hispanic**
  - 2011: 30.1%
  - 2012: 29.1%

- **Asian**
  - 2011: 16.8%
  - 2012: 15.1%


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Patient Navigation
Report to the Nation on Cancer and the Poor

In 1989 the American Cancer Society conducted a series of hearings throughout the country to hear the testimony of poor Americans who had been diagnosed with cancer.

American Cancer Society Cancer in the Poor a Report to the Nation 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 and suffering because of late stage disease.
Report to the Nation on Cancer and the Poor, 1989

Findings

- 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.
PRINCIPAL BARRIERS TO HEALTH CARE

- Financial
- Communication
- Health Care System Barriers
- Fear and Distrust
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 Model

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.
The Harlem Breast Cancer Experience
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*
### Harlem Hospital Center Breast Cancer Results Prior To Intervention 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>
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<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>
</table>

Harlem Hospital Center Breast Cancer Results Prior To Intervention

5 Year Survival Rate

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

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

### Comparison of Stage of Disease

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Stage 0</td>
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<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
National Legislation authorizing Patient Navigation Program

Signed into law
June 29, 2005
"Patient Navigator Outreach and Chronic Disease Prevention Act of 2005"
P.L. 109-18
Patient Navigation Across The Health Care Continuum

Freeman, 2006.
The Principles of Patient Navigation

Navigation is a patient-centric health care service delivery model.

The core function of navigation is the elimination of barriers to timely care across all segments of the health care continuum.

Patient navigation serves to virtually integrate a fragmented healthcare system for the individual patient.
The Principles of Patient Navigation

Patient Navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of all other providers. Navigators should be integrated into the health care team in such a way that there is maximum benefit for the individual patient.

Delivery of navigation services should be cost effective and commensurate with the training and skills necessary to navigate a individual through a particular phase of the care continuum.
The Principles of Patient Navigation

The determination of who should navigate should be primarily decided by the level of skills required at a given phase of navigation.

There is a need in a given system of care to define the point at which navigation begins and the point at which navigation ends.
The Principles of Patient Navigation

There is a need to navigate patients across disconnected systems of care such as primary care site and tertiary care sites. Patient navigation can serve as the process that connects disconnected health care systems.

Navigation systems require coordination. In larger systems of patient care this coordination is best carried out by assigning a navigation coordinator or champion who is responsible for overseeing all phases of navigation activity within a given health care site.
Three Major Factors to Improve Results

- Provide screening to patients regardless of ability to pay
- Establish patient navigation program
- Increase outreach and public education
Funding for Patient Navigation

- NCI 9 Demonstration Sites
- CMS 6 Demonstration Sites
- Health Resources and Services Administration 6 Demonstration Sites
- American Cancer Society
Funding for Patient Navigation

- Susan Komen Foundation
- Avon Foundation
- Pfizer Foundation
- Amgen Foundation
Cancer Program Standards 2012:
Standard 3.1
American College of Surgeons Commission on Cancer mandated that Patient Navigation is to be a standard of care to be met by cancer programs seeking approval beginning 2015
Affordable Care Act: 2010

The ACA requires that states utilize patient navigators to facilitate access to health insurance coverage for uninsured individuals.
Patient Navigation Impact on Clinical Outcomes

Research Findings
A 2011 review of the literature on patient navigation showed that patient navigation improves participation in cancer screening particularly in vulnerable populations.
National Cancer Institute
Patient Navigation Research Program (PNRP)
Research Findings
Major Research Finding:

The weight of evidence from the NCI PNRP indicates Patient Navigation can reduce the time from abnormal finding to diagnosis in breast, cervix, colorectal, and prostate cancer.

NCI Patient Navigator Research Program, 2012
NCI PNRP Study:

“Patient Navigation Improves Cancer Diagnostic Resolution: An Individually Randomized Clinical Trail in an Underserved Population”

Conclusions: Patient Navigation positively impacts time to resolution of abnormal screening tests for breast, colorectal and prostate cancers in a medically underserved population

Raich P. Cancer Epidemiol Biomarkers Prev; October 2012

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NCI PNRP Study:

“Boston Patient Navigation Program: Impact of Navigation on Time to Diagnostic Resolution after Abnormal Cancer Screening”

Conclusion: This study documents a benefit of patient on time to diagnosis in a racially/ethnically diverse inner city population.

Battaglia, T. Cancer Epidemiol Biomarkers Prev, October 2012
NCI PNRP Study:

“Patient Navigation Significantly Reduces Delays in Breast Cancer Diagnosis in the District of Columbia”

Conclusion: Navigated women, especially those requiring biopsy, reached their diagnostic resolution significantly faster than non-navigated women.
NCI PNRP Study:


Conclusions: Participants with abnormal screening tests or symptoms resolved faster if assigned to patient navigators.
NCI PNRP Study:

“Follow-up and Timeliness After an Abnormal Cancer Screening Among Underserved, Urban Women in a Patient Navigation Program”.

Conclusions: Patient navigation reduces time from abnormal cancer findings to definitive diagnosis in underserved women.

Markossian T. Cancer Epidemiol Biomarkers Prev; October 2012
Final Thoughts
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, September 2001
Patient Navigation Historical Time Table

1989  National Hearings on Cancer in the Poor
1990  Patient Navigator Program initiated at Harlem Hospital
2004  National Cancer Institute funded 9 demonstration sites
Patient Navigation Historical Time Table

2005  Patient Navigator Outreach and Chronic Disease Prevention Act

2006  Center for Medicare and Medicaid funded 6 demonstration sites

2008  Health Resources and Services Administration funded 6 demonstration sites (under the Patient Navigation Act)

2012  American College of Surgeons, Commission on Cancer mandates that patient navigation is a standard of care for cancer center approval

2012  Patient Navigation Assistance Act introduced into Congress
• No person in America with 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.
The unequal burden of disease in our society is a challenge to science and a moral dilemma for our nation.
Patient Navigation across the Health Care Continuum

Patient Navigation

Outreach

Abnormal Finding

Abnormal Results ➔ Diagnosis ➔ Treatment

Initial target in Harlem Model

Resolution

Survivorship

Prevention

Early Detection

Diagnosis/Incidence

Treatment

Post Treatment/Quality of Life

Freeman, 2006.

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