The History and Principles of Patient Navigation

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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

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
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
- 1995 “Expanding Access to Cancer Screening and Clinical Follow-up Among the Medically Underserved”, Cancer Practice 1995
  Freeman HP
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 Funded 6 Patient Navigator Sites

The Principles of Patient Navigation

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

2. Patient Navigation serves to virtually integrate a fragmented healthcare system for the individual patient.

The Principles of Patient Navigation

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

4. Patient Navigation should be defined with a clear scope of practice that distinguishes the role and responsibilities of the navigator from that of other providers.
The Principles of Patient Navigation

5. Delivery of patient navigation services should be cost-effective and commensurate to navigate an individual through a particular phase of the care continuum.

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

7. In a given system of care there is the need to define the point at which navigation ends.

8. There is a need to navigate patient across disconnected systems of care, such as primary care sites and tertiary care sites.


Patient Navigation Across The Health Care Continuum

Freeman, 2006.
The “War on Cancer”
Signing of the National Cancer Act of 1971

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

American Cancer Society Report on Cancer in the Economically Disadvantaged 1986

(CDC/National Center for Health Statistics Report 2006)
This discovery-to-delivery "disconnect" is a key determinant of the unequal burden of cancer.

**Causes of Health Disparities**

- Poverty/Low Economic Status
- Social Injustice
- Culture

Possible influence of gene-environment interaction

**The Discovery-Delivery Disconnect**

Critical Disconnect

This discovery-to-delivery "disconnect" is a key determinant of the unequal burden of cancer.

**Access to information and knowledge and Access to quality care**

**Prevention**
- Early Detection
- Diagnostic
- Incidence

**Diagnosis/Incidence**
- Treatment

**Post Treatment/Quality of Life**
- Survival and Mortality

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*Freeman, H.P., 2006*
The Meaning of Poverty

- Substandard housing
- Inadequate information and knowledge
- Risk-promoting lifestyles, attitudes, and behaviors
- Diminished access to health care

Culture

- Shared communication system
- Similar physical and social environment
- Common beliefs, values, traditions, and world view
- Similar lifestyles, attitudes, and behaviors

POVERTY

CULTURE

DECREASED SURVIVAL

Freeman, H.P., Cancer in the socioeconomically disadvantaged. Cancer 1989
Race
Perhaps the single most defining issue in the history of American society
In this nation we see, value, and behave toward one another through a powerful lens of “race”.

This lens can create false assumptions that may result in serious harm to members of some racial and ethnic groups.

Findings of IOM Report on Unequal Treatment, 2003

Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare.

Geographic Areas of Excess Cancer Mortality
A Black male in Harlem has less of a chance of reaching age 65 than a male in Bangladesh.

McLeod and Freeman, NEJM January, 1990

An Analysis of Excess Cervical Cancer Mortality—A Marker for Low Access to Health Care in Poor Communities

Cancer Mortality Rates by County (Age-adjusted 1970 US Population)
Cervix Uteri: White Females, 1970-98: Pooled White and Black Rates

NOTE: Shades of purple: ~ 100 counties each
Shades of green: ~ 300 counties each
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, 9%
  - 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
  - 12% some college
  - 11% high school, no diploma
  - 12% 4+ yrs. of college
  - 22% high school graduate

Source: National Cancer Institute INFORUM database

PRINCIPAL BARRIERS TO HEALTH CARE

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

Patient Navigation Model

Freeman, et al., Cancer Practice, 1995.
Patient Navigator 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.

Harlem Hospital Center Breast Cancer

Results Prior To Intervention

Screening Program

Stage of Disease

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<tr>
<th>Stage</th>
<th>1964-1986</th>
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<tbody>
<tr>
<td>Stage 0</td>
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<tr>
<td>Stage I</td>
<td>6%</td>
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<tr>
<td>Stage II</td>
<td>45%</td>
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<tr>
<td>Stage III</td>
<td>39%</td>
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<tr>
<td>Stage IV</td>
<td>10%</td>
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Five Year Survival Rate

Before access to screening & patient navigation (1964-1986)*
Impact of Harlem Hospital Center Breast Cancer Screening/Navigation Program
Comparison of Five-year Survival Rates (%)

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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>
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<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>
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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)*

Patient Navigation Across The Health Care Continuum

Freeman, 2006
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 Center’s 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.

Map of Harold P. Freeman Patient Navigation Institute Alumni

- Number of Institutions per state:
  - Alabama (3), Alaska (2), Arizona (1), Arkansas (4), California (24), Colorado (3), Connecticut (32), Delaware (1), Florida (4), Georgia (6), Hawaii (7), Idaho (1), Illinois (9), Indiana (2), Kansas (2), Kentucky (8), Louisiana (5), New Jersey (9), Maine (3), Maryland (8), Massachusetts (5), Michigan (4), Minnesota (3), Missouri (3), Montana (1), New Hampshire (1), New Mexico (4), New York (61), North Carolina (9), Ohio (5), Oklahoma (1), Oregon (1), Pennsylvania (9), Rhode Island (2), South Carolina (2), South Dakota (3), Tennessee (5), Texas (14), Virginia (1), Washington (2), West Virginia (1), Wisconsin (1)
  - St. Thomas, Virgin Islands (1), Bucharest, Romania (1), Toronto, Canada (1), London, England (1), Galway, Republic of Ireland (1)

Updated as of January 24, 2012
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

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

How can we eliminate health care disparities?
The Discovery-Delivery Disconnect

Critical Disconnect

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

We must apply what we know *at any given time* to *all* people, irrespective of their ability to pay.

Provide universal access to health care.

We must apply what we know *at any given time* to *all* people, irrespective of their ability to pay.
We must develop a comprehensive, unified approach to improving conditions rooted in poverty.

Delineate and target geographic areas with excess cancer mortality with an intense approach to providing culturally relevant education, appropriate access to screening, diagnosis and treatment, and improved social support.

Develop Patient Navigation Programs to provide personal assistance in obtaining timely and adequate diagnosis and treatment.
Create a high level of awareness among medical trainees and professionals regarding their role in eliminating bias in medical care delivery.

Establish and implement systems for monitoring treatment equity according to standards of care to diminish bias in the provision of health care.

Encourage each individual, regardless of economic status, to share in the responsibility for promoting his/her own health and well being.
Final Thoughts

Disparities in cancer are caused by the complex interplay of low economic class, culture, and social injustice, with poverty playing the dominant role.

Residents of poorer communities, irrespective of race, have higher death rates from disease. Within each racial/ethnic group, viewed separately, those living in poorer counties have lower disease survival.
There is evidence that race, in and of itself, is a determinant of the level of health care received.

Health disparities exact an extraordinarily high human cost and a significant economic cost to this nation.

People should not die from cancer because they are poor.
The unequal burden of disease in our society is a challenge to science and a moral dilemma for our nation.

“Knowing is not enough; we must apply
Willing is not enough; We must do.”

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.

Voices of a Broken System: President’s Cancer Panel 2002
Of all of the forms of inequality, Injustice in health is the most shocking and inhumane.

Dr. Martin Luther King Jr.