Historical Perspective of Patient Navigation and a Vision for the Future

National Cancer Policy Forum of the National Academies of Sciences, Engineering, and Medicine

November 13, 2017

Washington, D.C.

Harold P Freeman, M.D.
President & CEO, Harold P. Freeman Patient Navigation Institute
The “War on Cancer”

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

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
Causes of Health Disparities

Poverty/ Low Economic Status

Social Injustice

Culture

Possible Influence on Gene Environment Interaction

Prevention Early Detection Diagnosis Treatment Post Treatment/ Quality of Life Support

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

Freeman, H.P., Cancer in the socioeconomically disadvantaged. Cancer 1989
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.
Report to the Nation on Cancer and the Poor

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.
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.
Patient Navigation Model

Freeman, et.al., Cancer Practice, 1995.
Breast Cancer Stage of Disease  
Prior to Intervention (Harlem Hospital)

1964-1986

Stage 0  0%
Stage I  6%
Stage II 45%
Stage III 39%
Stage IV 10%

Harlem Hospital Center Breast Cancer Survival Prior to Intervention

Five 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>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<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

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

*After access to screening & patient navigation (1995-2000)*

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
The Principles of Patient Navigation

Navigation is a patient centered health care service delivery model.

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

Patient navigation may serve 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.

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

Who should navigate should be determined by the level of skills required in a given phase of navigation.

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

Patient navigation can serve as the process that connects disconnected health care systems such as primary care and tertiary care sites.

Navigation systems require coordination. In larger systems of patient care this coordination is best carried out by assigning a navigation coordinator who is responsible for overseeing all phases of navigation activity within a given health care system.
American College of Surgeons Commission on Cancer

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.
1989 National Hearings on Cancer in the Poor

1990 Patient Navigator Program initiated at Harlem Hospital

1995 **First publication on Patient Navigation:**
“Expanding Access to Cancer Screening and Clinical Follow-up Among the Medically Underserved”, J. Cancer Practice. 1995 Freeman HP

2004 National Cancer Institute funded 9 Patient Navigator demonstration sites

2005 Patient Navigator Outreach and Chronic Disease Prevention Act Signed into Law by President Bush
Patient Navigation Timeline

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)

2010  Affordable Care Act requires States to utilize Patient Navigators to facilitate access to health insurance

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

Patient Navigation Across The Health Care Continuum

Patient Navigation

Outreach

Abnormal Finding

Abnormal Results ➔ Diagnosis ➔ Treatment

Resolution

Survivorship

Prevention

Early Detection

Diagnosis

Treatment

Post Treatment/Quality of Life Support

Freeman, 2006.
Final Thoughts