Northwest Tribal Cancer Navigator Program

Patient Navigation:
Science, Traditions and Perspectives from Indian Country

NORTHWEST PORTLAND AREA INDIAN HEALTH BOARD
Overview

- What we know... the Facts, Theory, and Model
- Who are navigators and what do they do?
- Challenges
- Successes
- Looking Ahead
I would like to thank...

- All of the Tribal members who have contributed to our understanding of patient navigation in Indian Country

- Christine Merenda, Christine Ross, Chrissie Russell, Michelle Joseph, Frank Munoz, Ellen Doublerunner, Pam Young, Carole Komaromy, Sandra Hahn, Leah Hardy, Mary Loy, Jasen Henderson, Lin Razer, ChaceMickleson, and Laura Allen – Navigators

- Angela Mendez, Judy Muschamp, Roanna Stump, Rod Smith, Byron Larson, Anlot Wright, Lois McKee, Jay Sampson, DanialHocson, Dar Buena-Suerte, Donn Kruse, Cheryl Bittle, Clark Marquart, Doni Wilder, Leslie Dye, and Bill Freeman

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- Roland Garcia, Kenneth Chu and Martha Hare from the Center to Reduce Cancer Health Disparities, National Cancer Institute
MISSION:
To assist Northwest tribes to improve the health status and quality of life of member tribes and Indian people in their delivery of culturally appropriate and holistic health care.
NPAIHB Cancer Programming

- Comprehensive Cancer Control Program
  ○ Initiated in 1998 to form a Regional Cancer Action Plan
- Northwest Tribal Cancer Registry
  ○ Initiated in 1999 to assess the misclassification of American Indians / Alaska Natives in National and State cancer registries
- Northwest Tribal Cancer Navigator Program
  ○ Initiated in 2003 to address Cancer Health Disparities and Cancer Care Coordination
What We Know...
The Facts, Theory, and Model
National Landmark Reports Highlighting Cancer Disparities as a Problem

Findings:

- Poor people meet significant barriers when they attempt to seek diagnosis and treatment of cancer.
- 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.
- Current cancer education programs are culturally insensitive and irrelevant to many poor people.
Report Causes of Health Disparities

- Low Economic Status/Poverty
- Culture
- Social Injustice
There is a critical disconnect between what we discover and what we deliver to all American People.
### Stage at diagnosis, all sites, AI/AN versus White, Idaho, Oregon, and Washington, 1996-2001

<table>
<thead>
<tr>
<th>Stage at diagnosis</th>
<th>AI/ANs</th>
<th>Whites</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>n (% of all cases)</td>
<td>n (% of all cases)</td>
</tr>
<tr>
<td><strong>In situ</strong></td>
<td>150 (6.3)</td>
<td>27,346 (9.4)</td>
</tr>
<tr>
<td><strong>Local</strong></td>
<td>792 (33.0)</td>
<td>113,383 (39.0)</td>
</tr>
<tr>
<td><strong>Regional</strong></td>
<td>568 (23.7)</td>
<td>58,691 (20.2)</td>
</tr>
<tr>
<td><strong>Distant</strong></td>
<td>534 (22.3)</td>
<td>53,483 (18.4)</td>
</tr>
<tr>
<td><strong>Unknown/Unstaged</strong></td>
<td>356 (14.8)</td>
<td>37,659 (13.0)</td>
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Source: Cancer among Northwest AI/ANs: Using data linkage to improve incidence rates. Authors: Emily Puukka, Paul Stehr-Green, and Tom Becker.
Cancer Care Barriers

Cultural Barriers
- Fear of "contagious"
- Cancer is "punishment"
- Fear & stigma of cancer
- Do not ask questions
- Privacy
- Tribal approval is slow
- Fear of Federal Government

Patient Barriers
- Frequent moves
- Telephone
- Education
- Communication
- Inflexible clinic hours
- Transportation
- Child- & Elder care
- Comorbidities
- Insurance

Program & Administration Barriers
- Tribal misconceptions about Navigator program
- Data collection
- Staffing
- Tribal approval
- IHS eligibility
- Insurance

Navigator Barriers
- Comorbidities
- Trust
- Insurance
- Time involved working with outside agencies
- Non-Navigator clinic demands
- Cross-training
- Patients who lack family support
- Patient compliance
Northwest Tribal Cancer Navigator Program

- 2002: President’s Cancer Panel convenes on the Yakama Reservation
  - Directed by Harold Freeman, MD
- 2003: Pilot project funded by the Center to Reduce Cancer Health Disparities (CRCHD) of the National Cancer Institute (NCI)

Program Overall Aims

- Ensure that AI/AN patients have access to the same cancer care as others
- Navigators help patients overcome barriers to diagnosis and treatment
- The study will evaluate if Navigation works in our communities by
  - Enrolling patients at the four clinics
  - Recording data about their cancer journey
  - Comparing timelines and outcomes to control patients
Framework of the Patient Navigator Model

- OUTREACH
- PATIENT NAVIGATION
- REHABILITATION

Screening → Abnormal Finding → Diagnosis → Treatment → Survivorship
## Indian Health Care System

<table>
<thead>
<tr>
<th>Colposcopies</th>
<th>Cone biopsies</th>
<th>Sigmodoscopies</th>
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<tbody>
<tr>
<td>Urology services</td>
<td></td>
<td>Chemotherapy</td>
</tr>
<tr>
<td>Mammograms</td>
<td></td>
<td>PET scans</td>
</tr>
<tr>
<td>MRIs</td>
<td></td>
<td>Surgeries</td>
</tr>
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**CLINIC**
- Pap tests
- Clinical breast exams
- Digital rectal exams
- PSA tests
- Fecal occult blood tests

**Physical therapy**
NTCNP's Unique Set-Up

- Set in community clinics rather than in cancer centers
- Rural and semi-rural locations
- Navigators take on many roles, including outreach
- Assist patients with any type of cancer, not just screenable cancers
- Strive for proactive navigation
Who are Navigators? ...and What do they do?
Navigators: A Quick Glance

- The Navigators job is to keep the patient from getting lost, stuck, or ignored by the system.
- They function as a patient advocate, medical social worker, and case manager... all at once. 😊
- They come from various training backgrounds.
  - Nurses, Community Health Workers, Aspiring Physicians, etc.
- Navigators are expert problem solvers and extremely creative in coming up with “out of the box” ideas to overcome barriers.
Duties of the Navigators

- Assist Patients and their extended families
  - **Education:**
    - Provide information on prevention, screening, diagnostic procedures, disease course, treatments, community resources, and clinical trails
  - **Support:**
    - Provide or refer patients / family to emotional and psychosocial support services
  - **Coordination of Resources:**
    - Outreach activities, guide people through screening processes
  - **Facilitation of Services:**
    - Identify and address logistical barriers to care such as transportation, child & elder care and financial issues
Duties of the Navigators (cont.)

- Interacting with Providers and Health Care Systems
  - Provide and arrange translation services, assist patients and families in preparation of questions, and ensure information is understood
  - Address health systems barriers including coordinating appointments, facilitating referrals, facilitating patient-provider communication, coordinating multidisciplinary team of providers and completing medical paperwork
Duties of the Navigators (cont.)

- Interacting with Community
  - Engage and attend a variety of community health activities
  - Network and develop partnerships with local programs, organizations, and institutions to identify resources in the community such as screening facilities and financial assistance programs
  - Participate in cultural events within the community
Average Navigator Case Loads

20 to 30 patients per month

• 2 to 5 high-intensity patients
• 5 to 10 low- to medium-intensity patients
• 10 to 20 abnormal cancer screening test follow-ups
Patient Navigation: Examples

- Calling on the evening before a biopsy to make sure the transportation arrangements would still work out and to go over instructions for preparation
- Bringing a book of photos to show a young woman what a mastectomy scar would look like
- Attending consults with patients and talking with them afterward about what was said
- Getting doctors to talk to each other when they give conflicting advice
- Finding a traditional healer who will to talk to a patient about losing long, Indian hair during chemotherapy
## Issues Addressed During Encounters

<table>
<thead>
<tr>
<th>Issue</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Patient education</td>
<td>67%</td>
</tr>
<tr>
<td>Establishing eligibility, completing applications, making appointments</td>
<td>46%</td>
</tr>
<tr>
<td>Clarify provider information, attending appointment</td>
<td>38%</td>
</tr>
<tr>
<td>Listening to patient, counseling</td>
<td>37%</td>
</tr>
<tr>
<td>Complete chart, communicate information to team, pt</td>
<td>35%</td>
</tr>
<tr>
<td>Financial issues, including care assistance</td>
<td>21%</td>
</tr>
<tr>
<td>Helping patient cope with side effects or symptoms of cancer</td>
<td>20%</td>
</tr>
<tr>
<td>Connecting patient with support groups</td>
<td>16%</td>
</tr>
<tr>
<td>Family issues, elder care, child care</td>
<td>16%</td>
</tr>
<tr>
<td>Assisting patient with transportation</td>
<td>8%</td>
</tr>
</tbody>
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Challenges
Challenges

- Enrolling patients early – before diagnosis
- Provider buy-in
- Navigator burn-out and boundaries
Enrolling Patients Early

- Delayed diagnosis and treatment can lead to
  - increased patient anxiety
  - later stage at diagnosis and
  - worse survival outcomes.
This is especially important in our communities?

- Incidence for most common cancers similar to overall population
- Majority of disparities in AI/AN are in stage at diagnosis & survival
  - Caused by lack of insurance, fractured system, limited resources, distance from care, etc.
- These are the very things that are linked to delays
Loss to follow-up may occur due to:

- No IHS facilities to diagnose or treat cancer in the Northwest
- Provider’s heavy workload
- No standardized, comprehensive system for following patients after screenings
- Patient non-compliance due to:
  - Fear
  - Lack of understanding
  - Fatalism
  - Cannot afford care (or perception of this)
Focus on starting Navigation early

- “We must ensure that any woman with a positive finding will receive further diagnosis and treatment on a timely basis. There is a particularly critical window of opportunity to save lives from cancer between a point of suspicious finding and the resolution of the finding”

- “The most important role of Patient Navigation is to assure that an individual with a suspicious cancer-related finding will receive a timely diagnosis and treatment”
With Navigation being relatively new to many clinical settings, providers engagement proves challenging.

- Buy In is challenging as a result of a lack of trust.
  - What are you going to do with my patient?
- Lack of understanding of the navigator role.
  - Providers don’t understand what Navigators do and why it is important.
Navigators are always on the job in small communities.
- Grocery store, gas station, powwows

Perceived and expected job obligations
- Mentality of having to save everyone
- Stress of “fault” when a patient dies

Working on patient’s agenda and not the navigator’s agenda.
- But I can do this for you...
Successes... 😊
Successes

- Raising Awareness
- Improving Access to Care
- Financial, Housing, & Transportation
- Coordination of Care
- Bringing Support
Raising Awareness

- Preventive Care & Screening
  - Displays in clinics and around the community, Presentations, Health Fairs
    - HPV presentations at schools for students and parents
    - Men’s Health Fair “Pinch Cards”.
- Partnering with other programs to pool resources
  - Diabetes, Chronic Care, HIV, etc
- Utilizing Media
  - Newspaper (local and Tribal), Radio, TV
Improving Access to Care

- It is the Navigator’s duty to direct people to resources. However in rural Tribal communities, resources just don’t exist. In these cases, Navigators have taken the lead in creating the needed resources.

  - Mammo Van in Fort Hall, Idaho
  - Leveraging Funds from states
  - Outreach Events
    - Papathon
    - Men’s Wellness Conference
    - HPV Educational Sessions
Resources in rural areas are always difficult to come by and we have found that one of the most important underpinnings of a successful navigator program is a strong network of partners and community linkages on which they can draw.

- Examples
  - Angel Flight
  - Tribal Housing
  - Tobacco Tax funds
  - State and National Programs
Coordination of Care

- Coordinating a patient's healthcare team takes time and energy, but is an essential function of the Navigators' work.
  - Attending Case Management Meetings
  - Ensuring charts are complete and test results, consult letters, and pathology reports are communicated between providers
  - Keeping clinic staff informed of a patient’s progress
Bringing Support

- Navigators have also responded to the need for cancer support groups within their communities.
- They have attended training to be better informed on how to direct a support group – however the support groups have become quite self-sufficient and rely less on the Navigator.
- Support groups are taking on small projects such as fund-raising. 😊
Looking Ahead...
Thank You

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