How to Use “Native American Cancer Education for Survivors” to help Survivors

Ways to Use “Native American Cancer Education for Survivors” to Help Cancer Patients

Supported by:
National Center for Minority Health and Health Disparities
Native Navigators and the Cancer Continuum (NNACC) [NCMHD R24MD002811]

OBJECTIVES
By the end of this segment, the community participant will be able to:

1. Identify selected findings from the NACES.
2. Access and use the QOL NACES surveys and educational modules.
3. Identify ways the modules can be tailored for use with an individual cancer patient.
4. Interact with at least one QOL module in real-time.

What is NACES?
How can it Help with Local AIAN Cancer Patients

“Native American Cancer Education for Survivors” (NACES) supported by:

Susan G. Komen for the Cure® [#POP0503920] and [#POP0202135]
National Cancer Institute [NCI R25 CA 101938]
Mayo Clinic’s Spirit of Eagles Community Network Programs [NCI U01 CA 114609]

What is “Native American Cancer Education for Survivors”?

Web-based
FREE!!
Quality of life survey
Designed for breast cancer patients
But has information relevant to patients who have other types of cancer
Includes both genders
Tailored to the individual
Resource for those needing information
Research study
Culturally specific
Inter-tribal
Uses the Medicine Wheel and Circle of Life

“quality of life” – how well you are able to do everything you want to do: physically, mentally, emotionally, and spiritually

Components of NACES

- Education
- Culture
- Research
- Technology

Native Navigators and the Cancer Continuum (NNACC) [NCMHD R24MD002811]
How to Use “Native American Cancer Education for Survivors” to help Survivors

Internet Issues

- Lack of access and comfort among many community members.
- Addresses costs issues (mailing, returns, printing, printing errors)
- Addresses updating issues (allows for rapid update … sort of) and correction of errors
- Addresses access issues by providing Native Partners with laptops and training to help other survivors use the Page

Question asked of community members:

<table>
<thead>
<tr>
<th>Year</th>
<th>Yes, I could download the information myself</th>
<th>Yes, I could get someone to help me download the information</th>
<th>No, I’m not certain if I could get the information</th>
<th>No, I do not have access to the Internet</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002</td>
<td>15%</td>
<td>30%</td>
<td>30%</td>
<td>25%</td>
</tr>
<tr>
<td>2006</td>
<td>35%</td>
<td>40%</td>
<td>15%</td>
<td>10%</td>
</tr>
</tbody>
</table>

Overview of NACES Components

Purpose of NACES

Improve the QUALITY OF LIFE for American Indian, Alaska Native, North American Indian (AI/AN/NAI) women and men who are breast cancer survivors by:
1. Developing and testing culturally specific cancer education materials
2. Making the materials easily available through the internet
3. Helping survivors find resources to help them with their cancer issues

NACES is designed:

- For Native American breast cancer patients, Advocates and family and others who care about them.
- To give information that may help improve the patient’s quality of life.
- To include information that may be useful for those with other types of cancer.
How to Use “Native American Cancer Education for Survivors” to help Survivors

**Denver’s Native Sister Advocates**

Available by toll free phone (1-800-537-8295) to help patients obtain the information on the web site (e.g., uncomfortable or don’t know how to use the web, prefer to talk with live person)

**The Privacy Broker**

The only person who can access private information (e.g., when patient forgets her code name or needs some additional help or something mailed to her)

Alice Bradley, MA
Colorado Springs, CO
1-877-838-9359

**Privacy Broker**

Code Name

Encrypted database with name, address, phone, email

QOL Survey responses
Tracking through Content branches and leaves

**NACES Research Staff**

Code Name

Native Advocate

Native Partner

Contact Privacy Broker if feel the patient needs some medical follow-up

Help the patient load survey information and move around the “tree”

Analyze QOL Survey responses to
- prioritize Native-specific QOL issues
- new topics that need to be addressed
- how to modify the content on the branches and leaves
- Based on QOL Survey, expand or enhance the information

NACES is both an (1) educational information and (2) a research study
How to Use “Native American Cancer Education for Survivors” to help Survivors

NACES includes:

- Both broad and specific educational information arranged by topics
- Surveys to help you find information of most interest and use to you
- Storytellers (real life examples but combined from different Native patients)
- Native vignettes (real survivors sharing their stories)
- Examples of questions that you may want to ask your provider

Layout of the Quality of Life Tree Information

Patients click on leaves in the site

The hummingbird appears next to the current leaf being viewed

Code Name and Online Survey
How to Use “Native American Cancer Education for Survivors” to help Survivors

Example of Findings

Anonymous Information

Overall, do you feel you are ______ able to do everything you want to do on a daily basis?

<table>
<thead>
<tr>
<th></th>
<th>Phys</th>
<th>Spirit</th>
<th>Soc</th>
<th>Ment</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am never able to do everything I want to do</td>
<td>7.7%</td>
<td>4.1%</td>
<td>4.3%</td>
<td>2.2%</td>
</tr>
<tr>
<td>I'm not able to do most things I want to do</td>
<td>27.5%</td>
<td>8.2%</td>
<td>21.5%</td>
<td>Poor</td>
</tr>
<tr>
<td>I am able to do most things I want to do</td>
<td>41.8%</td>
<td>38.4%</td>
<td>34.4%</td>
<td>Okay</td>
</tr>
<tr>
<td>I am able to do everything I want to do</td>
<td>23.1%</td>
<td>49.3%</td>
<td>39.8%</td>
<td>Good</td>
</tr>
</tbody>
</table>

Characteristics

Diagnosed with breast cancer
- 34% - not diagnosed (family members)
- 6.4% - diagnosed with last year
- 14.9% - diagnosed between 1-4 years ago
- 44.7% diagnosed more than 5 years ago

Blood Quantum
- Full blood = 44.4%
- 75-99% = 12.2%
- 50-75% = 17.8%
- 25-49% = 11.1%
- Less than 25% = 14.4%

Characteristics

Told by Health Provider You have Problem:
- High blood pressure = 45.6%
- Diabetes = 45.6%
- Arthritis / Rheumatism = 30%
- Obesity = 33.3%
- Thyroid = 21.1%
- Habitual Tobacco Use = 26.2% (not to be confused with ceremonial use)
How to Use “Native American Cancer Education for Survivors” to help Survivors

Characteristics

- Close blood relative (parent, sibling, children) diagnosed with cancer = 81.6%
- NOTE: BRCA1, BRCA2, her2/neu do not explain this pattern
- Where genetic markers identified in AIANs = none in full-bloods and only 2 in mixed bloods

Characteristics

- How many close blood relative(s) have / had cancer:
  - 1 relative = 32.1%
  - 2 relatives = 21.4%
  - 3 relatives = 16.7%
  - 4 relatives = 7.1%
  - 5 or more relatives = 9.5%
- Of these blood relatives with cancer
  - 42.4% of the relatives had BREAST cancer
  - 70% diagnosed younger than age 50

Characteristics

- Where do you live?
  - On the reservation = 38.9%
  - In a rural setting, but not on reservation = 18.9%
  - In a city, town, village = 26.3%
  - I move back & forth among city, rez, rural = 15.8%

Characteristics

- How far from your home (one way) did you travel for cancer treatment
  - 0-25 miles = 16.7%
  - 26-50 miles = 11.7%
  - 51-75 miles = 8.3%
  - 76-100 miles = 16.7%
  - 101-200 miles = 20%
  - 201-300 miles = 15%
  - 301-400 miles = 11.7%

New Symptoms since Diagnosis

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Fatigue</th>
<th>Pain</th>
<th>Memory Problems</th>
<th>Insomnia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>32.6</td>
<td>26.1</td>
<td>16.3</td>
<td>14.1</td>
</tr>
<tr>
<td>No</td>
<td>67.4</td>
<td>73.9</td>
<td>87.7</td>
<td>85.9</td>
</tr>
</tbody>
</table>

Body aches = 35.9%
Changes in concentration = 6.6% (4.4% of overall total – unable to concentrate at all)
Feeling Moody = 22.8%

Symptoms Today

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Fatigue</th>
<th>Pain</th>
<th>Concentration</th>
<th>Neuropathy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not a problem</td>
<td>25.3</td>
<td>52.8</td>
<td>5.5</td>
<td>56.5</td>
</tr>
<tr>
<td>Few days a month</td>
<td>30.8</td>
<td>19.1</td>
<td>13.2</td>
<td>27.7</td>
</tr>
<tr>
<td>Once a week</td>
<td>11.0</td>
<td>5.6</td>
<td>24.2</td>
<td>5/4</td>
</tr>
<tr>
<td>Few days a week</td>
<td>17.6</td>
<td>10.1</td>
<td>49.9</td>
<td>5.4</td>
</tr>
<tr>
<td>Every day</td>
<td>15.4</td>
<td>12.4</td>
<td>14.3</td>
<td>12.0</td>
</tr>
</tbody>
</table>
How to Use “Native American Cancer Education for Survivors” to help Survivors

How useful do you feel?

<table>
<thead>
<tr>
<th></th>
<th>Overall%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>14.3</td>
</tr>
<tr>
<td>A little useful</td>
<td>19.8</td>
</tr>
<tr>
<td>Useful</td>
<td>24.2</td>
</tr>
<tr>
<td>Very useful</td>
<td>24.2</td>
</tr>
<tr>
<td>Extremely useful</td>
<td>17.6</td>
</tr>
</tbody>
</table>

Positive Changes from Having Cancer

<table>
<thead>
<tr>
<th></th>
<th>Overall%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>2.3</td>
</tr>
<tr>
<td>A few good changes</td>
<td>6.8</td>
</tr>
<tr>
<td>Good changes</td>
<td>21.6</td>
</tr>
<tr>
<td>A lot of good changes</td>
<td>33.0</td>
</tr>
<tr>
<td>A great deal of positive changes</td>
<td>36.4</td>
</tr>
</tbody>
</table>

Feeling Isolated Since Diagnosis

<table>
<thead>
<tr>
<th></th>
<th>Overall%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very isolated/alone</td>
<td>7.8</td>
</tr>
<tr>
<td>Occasionally isolated/alone</td>
<td>18.9</td>
</tr>
<tr>
<td>Rarely isolated/alone</td>
<td>15.6</td>
</tr>
<tr>
<td>Feel okay (not isolated/alone)</td>
<td>35.6</td>
</tr>
<tr>
<td>Feel well supported and not isolated/alone</td>
<td>22.2</td>
</tr>
</tbody>
</table>


- Code Name
- Survey
- Survivorship Info on the Tree Limbs
- Side bar:
  - Videovignettes
  - Story Tellers
  - Visitors’ Questions
  - Sample Patient Questions
  - Glossary