

Policy Development to Improve Quality of Life Outcomes of Breast Cancer Survivors in a Northwest Tribal Community

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Presentation Overview

Purpose:

Describe a translational science effort that emphasizes a participatory approach to policy development that targets change at the system and community level to support cancer survivorship care planning

Discussion will include:

- *Factors* that contribute to the need to address policy level support for follow-up care of breast cancer survivors after primary cancer treatment
- *Key elements* of a community-based participatory approach to support health policy change
- *Action strategies* used to implement change at the systems level in a community-based primary care setting



Significance of concern & Population

Northwest American Indian/Alaska Native Breast Cancer Survivors

- Breast cancer is a leading cause of cancer morbidity and mortality among AI/AN women¹
- Breast cancer is the second most common cancer among Northwest AI/AN²
- Breast cancer mortality rates are 2.7 times higher for Northwest AI/AN than non-Hispanic white women²
- Typically diagnosed at later stage with lower survival rates^{1,3}

Significance of concern & Population

Northwest American Indian/Alaska Native Breast Cancer Survivors

- Health disparities contribute to a decrease in survivorship^{4,5}
 - Lowest per capita income and lowest education attainment
 - Underfunded health care services and lack of access
 - Cultural differences
- Poorer outcomes “lost in transition”:
 - lack of monitoring and coordination of care following primary cancer treatment⁶
- Need for policy level quality improvement projects
 - Lack of policies to improve survivor quality of life
 - Local, regional, and national levels

Significance of concern & Population

Post-treatment issues that have the potential to impact quality of life for breast cancer survivors include:

- Physical changes (e.g. altered body/self-image, weight gain, lymphedema)
- Cardiotoxicity
- Neuropathy
- Osteoporosis
- Premature menopause, infertility
- Cognitive dysfunction
- Sexual dysfunction
- Fatigue
- Psychosocial concerns including fear of recurrence

Improving Cancer Survivorship through Advocacy

Timeline

- 1986 National Coalition for Cancer Survivorship established – Cancer survivorship and its stages defined
- 2002 President's Cancer Panel – Dialogue with Pacific Northwest Tribes on the Yakama Reservation
- 2004 President's Cancer Panel – Focus on Survivorship and the difficulties in transition in care
- 2005 Institute of Medicine Report - *From Patient to Cancer Survivor: Lost in Transition* called for the development of new tools

Improving Cancer Survivorship through Advocacy

Timeline

- 2007 American Society of Clinical Oncology – developed new evidence-based tools provide guidance for breast cancer follow-up and management
- 2008 Cancer survivorship – further defined with focus on the transition from specialty care to follow-up care that is likely to be provided by primary care providers in the community
- 2012 Commission on Cancer of the American College of Surgeons revise standards – Call for a *survivorship care plan* that documents care received and seeks to improve cancer survivors' quality of life.

Potential of survivorship care plans to improve survivor quality of life

- Provide a mechanism to identify the medical, functional, and psychosocial consequences of breast cancer and its treatment
- Define quality follow-up care for cancer survivors and identify a strategy to achieve it
- Help to identify and treat adverse effects of the primary treatment and detect recurrences early
- Support the patient's ability to cope by organizing services and psychosocial support

New Resources for Breast Cancer Survivors

American Society of Clinical Oncology *Breast Cancer Treatment Summary:*

- Contact information for specialists
- Final stage of breast cancer
- Pathology and biomarkers (hormone receptors and *Her2 status*)
- Type of Surgery
- Chemotherapy and amount received
- Other therapies (e.g. Radiation)
- Indications for additional therapies as appropriate
- Complications from therapies

New Resources for Breast Cancer Survivors

American Society of Clinical Oncology *Breast Cancer Survivorship Care Plan:*

- Evidence-based recommendations for surveillance of recurrence and new cancers
- Specific recommendations for health behaviors
- Genetic testing as appropriate
- Any treatment related toxicities experienced by the survivors
- Other potential long-term and late effects
- Psychosocial and supportive care needs and identification of providers to coordinate care

Sample Care Plans

- **American Society of Clinical Oncology (ASCO)** treatment summaries and survivorship care plans
 - <http://www.cancer.net/survivorship>
- **LIVESTRONG Foundation** treatment summaries and survivorship care plans
 - <http://www.livestrongcareplan.org/>
- **Journey Forward** online survivorship care plan builder
 - <http://www.journeyforward.org/>
- **Prescription for Living** post-treatment care plan developed by national group of nursing, social work, and survivor organizations. Sponsors included American Cancer Society, Oncology Nursing Society, the National Coalition for Cancer Survivorship, American Journal of Nursing, and the University of Pennsylvania School of Nursing
 - <http://www.nursingcenter.com/lnc/static?pageid=721732>

Project goal for system change

- Collaborate with tribe to develop policies that will:
 - Track and document follow-up care after completion of primary breast cancer treatment
 - Prepare primary care providers and other health center staff to assure this documentation
 - Develop educational strategies to empower women to expect coordination of care and appropriate follow-up screening

Approach to change

Theoretical Framework:

- Community organization and community building emphasizing the following key concepts⁷:
 - Empowerment
 - Critical consciousness
 - Community Capacity
 - Social Capital
 - Issue Selection
 - Participation and Relevance
- Diffusion of Innovations⁸ with emphasis on structural and system supports that facilitate the adoption of new resources

Approach to change

Community-based participatory approach adapted for policy research⁹

- Actively seeks to engage relevant stakeholders
 - Establish rapport and trust through participant observation and meeting felt needs
- Broadly frames the problem of interest
- Considers contextual factors of influence related to problem and setting including:
 - History
 - Culture
 - Social
 - Political

Action plan to meet objectives

- Formed project planning team
 - Health Director, Nurse Manager, Medical Social Worker, Breast Cancer Survivor Support Group members
- Assessed existing tribal policies and procedures
- Assessed current tracking and documentation practices and needs
- Collected data through chart review AND interviews with **Key Stakeholders**
 - healthcare providers
 - administrative staff
 - others involved in the care of survivors in the community
 - tribal council members
 - tribal elders
 - breast cancer survivors
 - family members and caregivers
- Synthesis of literature, program policies, and intervention strategies
- Collaborated with project planning team to develop policy recommendations
- Documented process and key findings for key stakeholders
- Disseminated findings – oral presentation and written reports



Planning Team Discussions/Review of Current Practice

Findings:

- Lack of existing policies to track and document breast cancer survivor follow-up care needs
- Current tracking and documentation system (Resource and Patient Management System-RPMS) inadequate to meet the follow-up needs of breast cancer survivors

- Consultation notes from outside oncology specialists are main source of key information about survivors' cancer experience including transition to follow-up care.
- ASCO breast cancer treatment summary and survivorship care plan templates approved as appropriate resources to adapt to help guide tracking and documentation of care and follow-up needs

Discussions/Informal Interviews with Breast Cancer Survivors

Questions used to guide discussions/informal interviews with breast cancer survivor support group members:

1. What type of information did you receive following the completion of your initial treatment for breast cancer?
2. Do you think the information provided on the ASCO breast cancer treatment summaries and survivorship care plans would have been helpful, and if so, how?

Discussions/Informal Interviews with Breast Cancer Survivors

Findings:

- Information will help to improve knowledge and understanding of diagnosis, and plan for follow-up care
- Information remains relevant for survivors several years post-treatment
- Support for the use of new resources (ASCO templates) unanimous

Recommendations:

- Tailor survivorship care plan to their individual needs
- Present information in language that is easy to understand
- Include traditional methods for healing after cancer treatment

Presentation/Discussions/Informal Interviews with Medical and Administrative Staff

Overview of presentation and discussion focus:

- Information on the background and significance of addressing post treatment follow-up care and survivorship needs of breast cancer survivors in the community
- Overview of the purpose and content of breast cancer treatment summaries and survivorship care plans
- Results of chart review
- Benefits and challenges of using new resources to improve quality of life outcomes for breast cancer survivors

Presentation/Discussions/Informal Interviews with Medical and Administrative Staff

Findings:

- Agreed improvements in the tracking and documentation of breast cancer survivor follow-up care and needs are warranted
- Agreed ASCO treatment summaries and survivorship care plans are appropriate resources to consider to meet this purpose
- Liked how resources provide a concise history of the patient's cancer experience that could be easily extracted from the medical record

- Suggested tailoring resources to meet the cultural needs of the survivors and tracking and documentation needs of Tribal Health Center
- Concerns were expressed about time constraints, staff resources to track documentation, and role definition

Outcomes

NEW approach/PLAN developed will:

- Implement a system to track and document the needs of women after primary therapy for breast cancer
 - Assessment of care needs
 - Appropriate referrals
 - Use new tracking tools
 - *American Society of Clinical Oncology Cancer Treatment Summaries and Survivorship Care Plans*
- Educate primary care providers, staff and women about use of new tools
- Assure women who have completed primary treatment for breast cancer that they will receive a comprehensive survivorship care plan

Outcomes

Quality Improvement (QI) Project Plan

- Accomplished 1st step in process of creating
 - systematic multidisciplinary approach to the careful tracking and documentation of care and follow-up needs of breast cancer survivors
- *Lessons learned* from QI Project
 - Importance of the infrastructure needed to support expansion of support services to all cancer survivors served by the Tribal Health Center.

Lessons learned

Ideas for Implementing Change

- Work collaboratively
- Think real world, what's achievable and measurable
- Commitment to the process
- Passion and Curiosity
- Be flexible, open to possibilities
- Seek to understand
- “*Context is everything*” – Wilma Mankiller, First Female Chief of the Cherokee Nation

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