Listen to the People
Perceptions of the South Dakota Comprehensive Cancer Control Plan

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Prevention of Cancer: Lower cancer-related risk factors

- Prevent tobacco use, help people quit using tobacco, and decreased second hand smoke exposure
- Increase healthy weight among South Dakotans
- Increase fruit and vegetable consumption
- Increase physical activity
- Encourage sun protection and educate on effects of using a tanning bed
- Promote HPV (human papilloma virus) vaccination
Cancer Control Plan for South Dakota 2011-2015

**Early Detection of Cancer:** Increase appropriate cancer screening

- Increase the number of persons age 50 and older who complete colorectal cancer screening (i.e., colonoscopy or fecal immunochemical testing (“FIT test”) of a stool specimen)
- Encourage healthcare providers to promote colorectal cancer screening to their patients
- Promote mammography screening for breast cancer
- Increase the number of women who have a PAP test for cervical cancer screening
Cancer Control Plan for South Dakota 2011-2015

**Cancer Treatment:** Reduce barriers to accessing quality cancer treatments

- Provide information about cancer treatment options, locations, and social service programs
- Reduce barriers to completing treatment by promoting assistance programs in the areas of transportation, lodging, and financial assistance for cancer drugs
- Promote patient-centered care
- Provide decision-support materials for early stage breast cancer
- Increase the number of cancer treatment centers reaching accreditation standards
Cancer Control Plan for South Dakota 2011-2015

**Quality of Life:** Advocating for survivors, caregivers and patients at end of life

- Increase the use of cancer survivor care plans
- Promote non-clinical support services for cancer patients and families
- Develop a model of patient navigation post-treatment
- Increase palliative care services
- Support caregivers of cancer patients
Purpose

• Conduct listening groups statewide to provide input on the current plan and report on current needs of South Dakotans affected by cancer.
Specific Aims

• Assess perceived strengths
• Assess perceived weakness
• Identify gaps in the SD CCC Plan
Design & Methods

- Descriptive design
- Focus group method
- Approved by South Dakota State University Institutional Review Board
Focus Groups

• Small rural = 1 focus group
• Large rural = 4 focus groups
• Urban = 5 focus groups
• 57 total participants
  – Ages: 25-80,
  – Female and Caucasian
• 2 focus groups consisted of health care workers
Results: Focus Group Question

What are the major cancer issues for people living in ___ community?
Lack of Knowledge

- Don’t know to avoid tobacco & sun”
- “People don’t know what tests they need” & doctors don’t push them hard enough to get recommended screenings”
- “Nobody talks about diet & cancer being related”
- “Education should start earlier”
- “Educate young people”
- Lack of knowledge about early detection
Access & Obtaining Care

- “Traveling to bigger cities physically exhausts cancer patients”
- “Need more outreach”
- “Limited cancer care providers”
- “Don’t have access to screening”
- “No public transportation to get to chemotherapy or specialty services in bigger cities (Sioux Falls)”
- “Treatment is too far away”
Complicated Insurance

- “Cost of prevention, diagnosis, and care”
- “Doesn’t remove barriers”
- “Need for patient advocates”
- “If have cancer or cancer in family, can’t get”
- “Insurance might not cover screening”
- “Insurance might not cover treatment”
- “Self-employed have a hard time getting affordable insurance”
Fear of the Unknown

– “People don’t always want to know or are afraid of treatment”
– “They hope if they ignore it, maybe it will heal itself”
– “Denial—afraid to get checked out”
– “Denial ➔ delay seeking care”
– “More denial if have few or no resources”
– “Give people more time to come to terms with their situation”
Focus Group Question

What are some of the good things about cancer control for people living in ________?
• **Treatment close to home**
  – “Excellent health care from diagnosis to end of life”
  – “Community support”
  – “Not having to travel most of the time”

• **Quality care**
  – “Primary care providers referring to specialists”
  – Recognized cancer care available in the region”

• **Education**
  – Education is making a difference”
  – Oncologists provide quality education”
  – “State has good ad program on colon cancer screening”
• **Fundraising**
  – “Fundraising events not only raise money, but also awareness”
  – “Hometown atmosphere”
• **Multiple screening programs**
  – “More programs for uninsured than previously”
  – Good state programs for breast, cervical, colon cancer screenings”
• **Patient support**
  – “Patient navigators, social workers, RN case managers”
• **Hospice care**
  – “Hospice care is staffed by the some of best people”
  – “There are good hospice programs”
  – “Warm, caring people giving care:

• **Expanded healthcare coverage**
  – “Improved access”
  – “Eliminating pre-existing conditions”
  – “Healthcare reform provides important coverage”
Focus Group Question

What are some the things that could be better about cancer care?
• **Need to broaden screening**
  
  – “No standard method to screen for certain cancers (throat, lung, ovarian)”
  
  – “Providers don’t always know current screening guidelines”
  
  – “Need improved reminder systems for screenings”
  
  – “Lower age limit for All Women Count”
  
  – “Uninsured cannot always access recommended screenings”
• **Holistic care in home community**
  – “Individualized care for each person in home community”
  – “Increase number of oncologists”
  – “Health of the person should drive healthcare not insurance”
  – “Assistance with papers and medical records by a neutral advocate”
  – “Offer research studies in home community”
• **Improve access**
  
  – “Radiation treatment sites are limited”
  – “Limited transportation to care resources”
  – “Housing for rural patients”
  – “It’s hard to take the bus if you have just had chemo”
  – “Transportation services sometimes available but only if there are volunteers”
  – “Better insurance available for farmers & self-employed”
• **Communication**
  – “Caring Bridge”
  – “Facilities and providers who listen to people”
  – “Direct communication—take away the mystery”
  – “Support groups for general and specific cancers”
  – “Cancer support groups in regards to patients and their families”
• **Financial coverage/programs**
  – “Need to link eligible patients to programs”
  – “No resources to help with genetic testing and counseling—It’s talked about & recommended, but no way to pay for it”

• **Psychosocial support**
  – “Cancer diagnosis is psychologically & socially draining”
  – “Support for family is lacking”
• **Community Education on Prevention & Services**
  – Provide integrated list of services in the community”
  – “Improve cancer awareness in men”

• **Transparency of guidelines and regulations of screening & treatment**
  – “Program guidelines unclear and restrictive”
Focus Group Question

What are your ideas about programs or changes that could be made to improve cancer control for residents of ______?
• **Prevention**
  
  – “Establish a prevention center”
  
  – “Start screening earlier”
  
  – “Work with community agencies like YMCA, Parks & Rec on cancer prevention
  
  – Education on Primary and Secondary Prevention
  
  – “Educate providers on screening and testing”
  
  – “improve awareness of environmental factors”
• **Financial assistance**
  – “Promote funding and programs”

• **Improvement in palliative care**
  – “Educate about palliative care”

• **Culturally sensitive care**
  – “Culture affects cancer awareness & perceptions”

• **Quality improvement**
  – “Improve provider education on standards”
• **Support**
  – “Support groups to decrease fear”
  – “Support for care-givers”
• **Research**
  – “Access to participate in studies limited”
  – “Education on research process”
• *Increase programs for patients with cancer*
  – Integrative programs
  – Promote self-care
  – Promote private funding
  – Coordination between facilities
Priorities of SD Comprehensive Cancer Control Plan & Focus Group Themes
Prevention

• Lack of Knowledge
• Education
• Lack of Awareness
• Primary Prevention
Early Detection

• Lack of Knowledge
• Access to Care
• Fear of Unknown
• Evidence Based Screenings
Treatment

- Access/Obtaining Care
- Close to Home
- Quality Care
- Patient Support
- Insurance

- Culturally Sensitive Care
- Evidence Based Practice
- Research
- Expanded Healthcare Coverage
- Need for Transparency
Quality of Life

• Support
• Holistic Care in Home Community
• Communication
• Increase Programs for People with Cancer
Lack of Knowledge
- Prevention
- Early Detection

Access to Care
- Early Detection
- Treatment

Evidence Based Practice
- Early Detection
- Treatment

Support
- Treatment
- Quality of Life
Recommendations

• Strengthen access to cancer care for South Dakotans through increased programming and providing education on existing programs

• Expand availability of cancer support services; used of navigators & social workers
Recommendations

• Provide education on the importance of evidence based care & culturally sensitive care to all members of the health care team

• Educate third party payers on clinical practice guidelines for screenings; cost savings of screening coverage; & clinical trial enrollment
Recommendations

• Educate South Dakotans on importance & cost savings of prevention & early detection
  – Target adolescents through family, school, internet, or social media on behavioral cancer risks

• Promote and expand access to palliative & end of life care services, particularly in rural areas.
Questions?
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