

Listen to the People

Perceptions of the
South Dakota Comprehensive Cancer Control Plan

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Becky Randall, EdD, RN; Linda Burdette, PhD, RN; Gina
C. Rowe, DNP, MPH, FNP-BC; Jennifer Kerkvliet, MA,
LPC; Nancy Fahrenwald, PhD, RN, APHN-BC



Cancer Control Plan for South Dakota 2011-2015

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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