Bridging the Gap: Exploring Rural-Urban Cancer Disparities: 3rd Rural Cancer Disparities WUSTL Siteman – SIU SSM Partnership Retreat

Friday, March 17th, 2017
Simmons Cancer Institute, Springfield, IL

Presented by:
Retreat Agenda

9:30-10:00 Opening Remarks
Dr. Brard and Dr. Colditz

10:00-10:45 Pilot Project updates
Dr. Linnenbringer, Dr. Politi, Dr. Sharma

10:45-11:00 Break

11:00-12:00 Rural Disparities: Significance and Opportunities for Research
Dr. Cynthia Vinson

12:00-1:15 Lunch and networking

1:15-1:45 Southern Illinois Cancer Related Resources
Mr. Woody Thorne and Ms. Angie Bailey, SIH

1:45-2:00 Closing Remarks
Dr. James and Dr. Jenkins
What is the Rural Cancer Disparities Partnership?

A partnership between Simmons Cancer Institute of SIUSM and Siteman Cancer Center of WUSTL funded by the NCI Feasibility Studies to Build Collaborative Partnerships in Cancer Research (P20) Program.

NCI designed this P20 to promote and build collaborative research, training, career development, and education between the Institutions and NCI Cancer Centers or highly integrated cancer research programs.
The P20 initiative is part of the NCI Partnerships to Advance Cancer Health Equity (PACHE) Program.
Why is this important?

- Rural populations experience lower access to health care along dimensions of **affordability, proximity and quality**.

- Rural populations often experience higher rates of cancer, poorer survival, and less utilization of preventive services.

- The health gap between rural and other residents is **widening** according to recent data.
The partnership **GOALS** are to:

- Plan, prioritize, and implement a collaborative partnership in cancer-related and cancer-disparities research, and **researcher training, education, and career development** that is relevant to the population of Downstate Illinois.

- By doing so, the Partnership will contribute to **reducing** and eventually **eliminating** these rural cancer disparities.
The partnership **AIMS** are to:

- **Promote** new, integrated research collaborations between SCI-SIUSM and SCC-WUSTL to address cancers that disproportionately affect rural populations in Downstate Illinois.

- **Establish** a training and career development program for scientific and career development of SIUSM investigators while enhancing SCC investigators’ rural cancer disparities awareness, research, and reach.
The partnership **AIMS** are to:

- Create a research environment that:
  - *Enriches* research-related learning/training opportunities at SIUSM
  - *Promotes* mentorship and collaboration among clinical, population health, and basic science faculty/trainees at SIUSM and SCC
  - *Supports* investigators at both institutions by funding pilot projects that lead to preliminary data for future NIH/NCI grant applications.
Components of the P20 Grant

Pilot Research Projects

Training, Education and Career Development Program

Administrative Core
Pilot Research Projects

YR1 (2015-2016) pilot project
▪ “Disparities of health literacy in the context of kidney cancer and smoking”. PIs are Dr. Danuta Dynda (SIUSM) and Dr. Erin Linnenbringer (SCC).

YR2 (2016-2017) pilot projects
▪ “Supporting decisions about cancer clinical trials in rural cancer centers”. PIs are Dr. Swati Pathak (SIUSM) and Dr. Mary Politi (SCC).
▪ “Assessing head and neck cancer awareness as a function of rural residence”. PIs are Dr. Arun Sharma (SIUSM) and Dr. Lauren Arnold (SCC).
The CCDRP provides support for pilot research projects representing collaborations between investigators from both institutions. These pilot projects must:

- Specifically address cancer disparities relevant to Central or Southern IL
- Have at least one investigator from each site with a significant role

Assistance finding collaborators at partner institutions is available. New and early-stage investigators are strongly encouraged to apply!

**Letter of Intent due:** April 1, 2017  
**Full application due:** May 15, 2017  
**Funding Potential:** Maximum $50,000 in direct costs over one year

For more info, check out [www.ruralcancerdisparities.wustl.edu](http://www.ruralcancerdisparities.wustl.edu)
Multilevel Intervention in Cancer Care Delivery: Building from the Problem of Follow-up to Abnormal Screening Tests

Rural populations have lower colorectal cancer (CRC) screening rates due to barriers such as fewer specialists and distance to care for residents.¹

FOBT (fecal occult blood test) is more often used in rural areas.² Yet, few studies of follow-up after positive FOBT focus on rural areas.

Dr. Rebecca Lobb and Dr. Aimee James (WUSTL) partnered with Southern Illinois Healthcare (SIH) to develop and implement an intervention to improve CRC follow-up after positive FOBT with the goal of reducing CRC mortality in Southern Illinois.

Building from the Problem of Follow-up to Abnormal Screening Tests

- SIH team compiled most recent data to answer the following:
  - % of eligible patients that had completed CRC screening
  - # of positive FOBT tests
  - % of each type of follow-up (GI visit, colonoscopy, sigmoidoscopy, or not reported)

- Based on the data, WUSTL researchers determined there is significant room for improvement in:
  - Quality of patient data capture (minimize missing data)
  - Follow-up after abnormal CRC screening (maximize follow-up rate)

This submission is currently under review.
Clinical Sequencing Evidence-Generating Research (CSER2) – Clinical Sites (U01)

Establish Clinical Sites that cover a broad spectrum of healthcare settings and serve ethnically, socioeconomically and clinically diverse patients to:

1) Generate and evaluate evidence on the clinical utility of genome sequencing
2) Research critical interactions among patients, family, practitioners, & labs that impact implementation of clinical genome sequencing
3) Identify and address barriers to integrating genomic, clinical and healthcare utilization data within a health system to facilitate clinical decision-making
Siteman Strengths & BJC Collaborative

A critical gap in translating genomic sequencing results into clinical applications exists...a communication tool to aid clinical decision-making before & after genome testing may help bridge this gap.

Serve rural patients, low-income, African Americans
CSER2 builds on Siteman and P20 Collaborations

Patient diversity of 25% or more expected (racial or ethnic minorities, underserved populations or populations with poorer health outcomes).

Our AIMS:
1) Establish rapid workflow model to report genome sequencing results in lung adenocarcinoma and normal tissues. Enroll 1100 patients.
2) Explore stakeholders’ perceptions of challenges to delivering comprehensive genomic profiling for lung adenocarcinoma.
Aim 3: Develop a Clinical Communication Tool (CCT)

To address need for effective communication of benefits/risks of genomic sequencing and its clinical applications among patients, family, clinicians, and other stakeholders.
Aim 4: Genomic Decision Support Platform

Design, implement, & evaluate the deployment of a genomic decision support platform

• **On-line Reasoner for Comprehensive Health Information Delivery (ORCHID)**
• Capable of interoperating with commercial EHRs
• Has activity-feed interface to help interpret complex genomic, clinical, and healthcare utilization data by providers and patients.
Clinical Communication Tool in Shared-Decision Making Process

Online Reasoner for Comprehensive Health Information Delivery (ORCHID):
Genome decision support platform

- Treatment decisions
- Clinical trial participation
- Risk reduction behaviors

Improved Outcomes
Significance and Impact of the Study

- Translation of genomic testing to routine clinical practice
- Create a “next generation” framework for genomic decision support
- Modifiable for broader use in other precision oncology settings
- Increase the number of cancer patients who receive risk-stratified, targeted treatment based on clinical and genomic information
- Increase enrollment and participation in clinical trials
- Improve patient’s outcomes
- Build collaborations and serve as platform for additional collaborative studies
Training and Education Progress Highlights

- Learning activities, short term lab exchange and rural health seminar
  - SCC has provided access to their Works in Progress meetings where investigators can discuss grant proposals and get feedback from other investigators. SCC has also invited SIUSM investigators to join their journal club which meets the first and third Wednesday of each month.
  - Dr. Adetunji Toriola (SCC) took advantage of the short term lab exchange program and spent time with Dr. Buck Hales and Dr. Karen Hales who are SISUM faculty at the Carbondale campus. He presented some of his work on Vitamin D and cancer risk and toured the Hales’ lab to learn about their ovarian cancer hen model. Dr. Hales (SIUSM) along with Dr. Brard (SIUSM P20 PI) and Dr. Adetunji Toriola (SCC) were invited to submit a full grant application to the DOD OCRP (August 2016). Their research goal is to investigate novel biomarkers for early detection of ovarian cancer using the laying hen model and validate these presumptive biomarkers in clinical samples.
  - Dr. Sabha Ganai (SIUSM) presented the first rural health disparities seminar in October 2015 entitled “Using Health Geographics to Assess Cancer Disparities”. This seminar was video conferenced to SCC.
  - In May 2016, the partners conducted their first joint Interdisciplinary Population Health Sciences Research Group (IPHRSG) seminar. This seminar was previously limited to SIUSM investigators. At the June 2016 meeting, which was videocast, one SCC investigator presented along with one SIUSM investigator.
Training and Education Progress Highlights

▪ MPHS program/Training Program
  ▪ Dr. David Steward (SIUSM) visited with all clinical department heads at SIUSM to discuss potential applicants to this program using an informational flyer jointly developed by SCC and SIUSM. This lead to the enrollment of Carolyn Pointer, JD (Medical Humanities Department)
  ▪ Attorney Pointer enrolled and completed Dr. Aimee James’ Epidemiology course utilizing distance learning opportunities
  ▪ WUSM medical student worked with the team for a summer research rotation on rural health. She has attended P20 activities and is working with Drs. James and Linnenbringer to conduct a research project
Administrative Core Progress Highlights

- Successful initiation and completion of the collaborative pilot projects
- Successful application to NIH, NCI or similar external funding for independent research
  - Jenkins/Lobb R21 NINR application - Faith Community Nurses to Improve the Colorectal Cancer Screening Process in Rural Areas (scored) – Will be resubmitted
  - Jenkins R21 application - HPV-associated Oral Cancers: Epidemiology and Chlamydial Influences (triaged)
  - Jenkins R21 application - Assessment of Environmental Carcinogen Exposure in Rural Illinois Homes (triaged)
  - Diaz-Sylvester /Brard R50 NCI - Rural Cancer Disparities and Biomarker Discoveries (triaged)
  - Jenkins/James/Brard R25 NCI application - Focused Education in Rural Cancer Disparities Research (submitted Jan 2017)
Administrative Core Progress Highlights

- Sustainability of collaborative research programs/projects
  - Zahnd/Diaz-Sylvester/Brard/Colditz - Rural-Urban Differences in Surgical Treatment and Regional Lymph Node Examination in Endometrial Cancer Patients
  - Zahnd/James/Jenkins/Colditz/Steward/Brard - Rural-Urban Differences in Cancer Incidence and Trends in the United States
  - U54 grant proposal planning in progress to further our SIUSM-SCC collaboration
Administrative Core Progress Highlights

- Presentations and publications in cancer or other biomedical research
  - Dr. Aimee James and Dr. Wiley Jenkins presented a poster entitled “Addressing rural cancer health disparities: a Siteman - SIUSM partnership” at the PACHE meeting in June 2015
  - Whitney Zahnd (PhD candidate) presented at the American Association of Cancer Research sponsored Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved meeting an abstract titled “Rural-Urban and Access to Care Disparities in Cervical Cancer Stage at Diagnosis”. Her co-authors were Amy McQueen (SCC), Rebecca Lobb (SCC) Paula Diaz-Sylvester (SIUSM) and Laurent Brard (SIUSM/P20 co-PI)
Published Manuscripts Listing P20 Support:

- Jenkins WD, Botchway A. Young adults with depression are at increased risk of sexually transmitted disease. Prev Med, 88, 86-89.
Administrative Core Progress Highlights

- **Manuscripts Under Review Listing P20 Support:**
  - Javadi P, Sharma A, Zahnd WE, Jenkins WD. Evolving disparities in the epidemiology of oral cavity and oropharyngeal cancers
  - Jenkins WD, Lausen H, Pearson WS. Enhancing and promoting sexual health by coordinating and augmenting sexually transmitted infection screening in clinical venues
  - Ayyagari VN, Diaz-Sylvester PL, Hsieh THJ, Brard L. Evaluation of the cytotoxicity of the Bithionol - Paclitaxel combination treatment in a panel of human ovarian cancer cell lines.
P20 PILOT PROJECT:
Disparities of Health Literacy in the Context of Kidney Cancer and Smoking
Project team

SIU School of Medicine
Danuta Dynda, MD
  • Co-PI

Kevin McVary, MD, FACS
  • Co-investigator/mentor

WU School of Medicine
Erin Linnenbringer, MS, PhD
  • Co-PI

Katina Richardson, MD
  • Research coordinator

Nirek Sharma
  • Undergraduate research assistant (Summer 2016)
Kidney Cancer: Prevention & control issues

- Kidney cancer (CaK) mortality rates are significantly higher among individuals diagnosed with later-stage disease.

- There are no efficacious methods for CaK screening.

- Primary prevention via reduction of modifiable risk factors (e.g., smoking) and prompt diagnosis following early symptoms of the disease are key to reducing CaK mortality.
Kidney Cancer: Regional perspective


Kidney Cancer: Sociobehavioral perspective

Relationships among social & behavioral risk factors have not been adequately examined

• With regards to kidney cancer
• With regards to urban/rural disparities
Pilot Project: Research approach

Survey a total of 300 patients (ages 40+, no personal history of CaK) from 5 urology and primary care clinics

By geographic region (urban vs. rural):

1) Examine health literacy and cancer literacy

2) Investigate smoking status and knowledge of the relationship between smoking and kidney cancer

3) Compare threshold for bother caused by general urologic symptoms
Study start-up: challenges & solutions

- Coordinating IRB applications and protocols across sites
- Streamlining data collection and entry processes
  - Planned use of scantron software no longer available / feasible → switch to REDCap via Android tablets
  - Learning curve associated with new technology; required changes in the informed consent process
- Reaching a WUSM-associated primary care population
  - Working with ICTS Recruitment Enhancement Core to expand reach
**Current sociodemographics (as of 3/10/17)**

<table>
<thead>
<tr>
<th></th>
<th>Washington University</th>
<th>Southern Illinois University</th>
<th>Total (n = 194)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urology (n=67)</td>
<td>PCP/registry (n=34)</td>
<td>Urology (n=55)</td>
</tr>
<tr>
<td><strong>Age:</strong> mean (SD)</td>
<td>65.7 (8.4)</td>
<td>58.5 (11.2)</td>
<td>61.3 (9.9)</td>
</tr>
<tr>
<td><strong>Gender:</strong> n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>66 (98.5)</td>
<td>13 (38.2)</td>
<td>36 (66.7)</td>
</tr>
<tr>
<td>Female</td>
<td>1 (1.5)</td>
<td>21 (61.8)</td>
<td>18 (33.3)</td>
</tr>
<tr>
<td><strong>Race:</strong> n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>19 (28.4)</td>
<td>6 (8.2)</td>
<td>4 (7.4)</td>
</tr>
<tr>
<td>White</td>
<td>47 (70.2)</td>
<td>27 (81.8)</td>
<td>48 (88.9)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (1.5)</td>
<td>0 --</td>
<td>2 (3.7)</td>
</tr>
<tr>
<td><strong>Ethnicity:</strong> n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>0 --</td>
<td>0 --</td>
<td>1 (2.1)</td>
</tr>
</tbody>
</table>
Current sociodemographics (as of 3/10/17)

<table>
<thead>
<tr>
<th>Education level: (n, %)</th>
<th>Washington University</th>
<th>Southern Illinois University</th>
<th>Total (n = 192)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urology</td>
<td>Primary care</td>
<td>Urology</td>
</tr>
<tr>
<td>Less than high school</td>
<td>5 (7.6)</td>
<td>1 (2.9)</td>
<td>5 (9.4)</td>
</tr>
<tr>
<td>High school degree</td>
<td>18 (27.3)</td>
<td>6 (17.7)</td>
<td>20 (37.7)</td>
</tr>
<tr>
<td>Associate / technical degree</td>
<td>16 (24.2)</td>
<td>6 (16.7)</td>
<td>13 (24.5)</td>
</tr>
<tr>
<td>Bachelor degree</td>
<td>11 (16.7)</td>
<td>13 (38.2)</td>
<td>9 (17.0)</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>16 (24.2)</td>
<td>8 (23.5)</td>
<td>6 (11.3)</td>
</tr>
</tbody>
</table>
# Current sociodemographics (as of 3/10/17)

<table>
<thead>
<tr>
<th>Residential zip code: (n, %)</th>
<th>Washington University</th>
<th>Southern Illinois University</th>
<th>Total (n = 194)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urology</td>
<td>Primary care</td>
<td>Urology</td>
</tr>
<tr>
<td>Metropolitan area, RUCA 1-3</td>
<td>52 (77.6)</td>
<td>31 (91.2)</td>
<td>37 (67.3)</td>
</tr>
<tr>
<td>Micropolitan area, RUCA 4-6</td>
<td>7 (10.5)</td>
<td>0 (0)</td>
<td>7 (12.7)</td>
</tr>
<tr>
<td>Small town or rural, RUCA 7-10</td>
<td>8 (11.9)</td>
<td>3 (8.6)</td>
<td>11 (20.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Metropolitan area: UA = urbanized area</th>
<th>Micropolitan area: Large UC = urban cluster of 10,000-49,999</th>
<th>Small town or rural: Small UC = urban cluster of 2,500-9,999</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = core; primary flow within an UA</td>
<td>4 = core; primary flow within a large UC</td>
<td>7 = core; primary flow within a small UC</td>
</tr>
<tr>
<td>2 = high commuting; flow ≥ 30%</td>
<td>5 = high commuting; flow ≥ 30%</td>
<td>8 = high commuting; flow ≥ 30%</td>
</tr>
<tr>
<td>3 = low commuting; flow 10-30%</td>
<td>6 = low commuting; flow 10-30%</td>
<td>9 = low commuting; flow 10-30%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10 = Rural area; flow outside UA / UC</td>
</tr>
</tbody>
</table>
What does “rural” mean?

<table>
<thead>
<tr>
<th>County / City</th>
<th>2010 Population:</th>
<th>2010 RUCA codes (# tracts)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
<td>Density</td>
</tr>
<tr>
<td>St. Louis city</td>
<td>319,294</td>
<td>5,157.5</td>
</tr>
<tr>
<td>St. Louis County</td>
<td>998,954</td>
<td>1,967.2</td>
</tr>
<tr>
<td>Macoupin County</td>
<td>47,765</td>
<td>55.4</td>
</tr>
<tr>
<td>Sangamon County</td>
<td>197,465</td>
<td>227.4</td>
</tr>
<tr>
<td>Springfield</td>
<td>116,250</td>
<td></td>
</tr>
<tr>
<td>Jackson County</td>
<td>60,218</td>
<td>103.1</td>
</tr>
<tr>
<td>Carbondale</td>
<td>25,902</td>
<td></td>
</tr>
<tr>
<td>Williamson County</td>
<td>66,357</td>
<td>157.9</td>
</tr>
<tr>
<td>Marion</td>
<td>39,437</td>
<td></td>
</tr>
</tbody>
</table>
Observations & implications for future work

• Using WUSTL’s institutional access to the REDCap Android app is an effective and cost-efficient way to standardize data collection, entry, storage, and analysis across sites.

• Establishing uniform practices for clinic-based recruitment & enrollment can be challenging due to wide variation in clinic organization, patient flow, and provider subspecialities across geographic locations.

• Future analyses may need to account for outcome variation by both clinic site & residential area, as well as consider alternative or more finely-tuned urban-rural definitions.
Questions & Comments
Supporting Decisions about Cancer Clinical Trials in Rural Cancer Centers

Mary C. Politi, Ph.D.¹ and Swati Pathak, M.D.²

¹Washington University in St. Louis School of Medicine, Siteman Cancer Center
²Southern Illinois University School of Medicine, Simmons Cancer Center
Acknowledgements

- Kathy Robinson, PhD
- Nageen Mir, MPH
- Denise Monti, BA

This project was supported by grant number P20CA192966 from the National Cancer Institute as part of Addressing Rural Cancer Health Disparities: an SCC-SIUSM Partnership
Cancer Clinical Trials (CCTs)

- Vital to advance evidence-based cancer treatment
- ~3% of adult cancer patients participate in a CCT
- Fewer rural patients enroll
- Meta-analysis of 103 studies: > 25% did not understand the nature of the study or voluntary participation
- ~ 50% of participants understood central trial concepts such as the use of placebos or randomization

1 Murthy VH, et al. JAMA 2004
Why Don’t People Participate in CCTs?

• Fear-based barriers\(^1\)
  • Randomization
  • Placebos
  • Possible side effects
  • Possible impact on relationship with physician

• Misconceptions\(^2\)
  • “Last resort” after standard treatment

---

Key Elements Often Missing from IC Process

• Patients often do not carefully read forms\textsuperscript{1}
  • Written at very high reading levels\textsuperscript{2}
  • Long, cumbersome forms\textsuperscript{3}
  • Information appears irrelevant for participation\textsuperscript{4}

• Few ask questions or engage with clinicians about trials\textsuperscript{5}

  “Tell me what you would do”

\textsuperscript{3} Silverman HJ, et al. Critical Care Medicine 2005
\textsuperscript{5} Flory J, et al. JAMA 2004
CHOICES Development: Overview

- Web-based DA
- Patient stories
- Supplement to existing consent procedures
Making a choice about joining a cancer treatment research study

“When my doctor asked if I would join a research study trying new ways of treating my cancer, I didn’t understand. I didn’t know what would happen in a study or how it could affect my treatment. I trusted my doctor, but this was a big decision for me and my family. I learned all I could and then I made my choice. This website can help you learn and make your choice.”

“When I was asked to join a cancer research study, I got worried. I thought maybe there was no hope for me. Or, maybe they wanted to try some new treatment that wouldn’t work. I didn’t want to be a guinea pig. My worries went away as I learned more about research studies. You can learn more on this website and make the right choice for you.”

This website is about cancer clinical trials.

Cancer clinical trials help doctors learn if new drugs or treatments help cure or slow the growth of cancer. Other clinical trials may focus on how to prevent cancer or find it early. But, this website is about just treatment trials.

A cancer clinical trial may also be called a cancer treatment research study.

If you have been asked to join a clinical trial, this is the same as a cancer treatment research study. On this website, we will call cancer treatment research studies just cancer research studies or research studies.

Cancer research studies may be a choice for treatment when you have cancer. On this site we will be sharing general information about your choice to participate in cancer research studies and not information on any one research study in particular.

[Click here to learn how to use this site]
This page shows what matters to you when thinking about joining a study. Look it over and make sure you feel that the answers are right for you. Change any answers you want. If you change an answer, that statement may move up or down the list to show how important it is to you.

Once you feel like all the answers are right for you:
- print this page if you want
- use it to help you think about
  - what’s important to you
  - how you feel about joining a study

### Reasons to be in a study

- I believe being in a study might possibly improve my health.
- It is important to me to help others with this disease in the future.
- It is important to me to have more than the usual treatment.

### Concerns about being in a study

- I am worried about side effects.
- I am worried about the time commitment required.
- I would feel like a guinea pig if I were to participate.
- I am worried about the procedures that I might have to go through.
Some studies divide patients into 2 groups

- In Phase 3 studies, patients are put into groups at random, this is also called randomization.

- Half the patients get the standard treatment or drug. Half get the new treatment or drug. Which group you are in is decided by chance, like the flip of a coin.

![Diagram showing randomization](image)

**Standard treatment**  
A computer, not the doctor, decides which treatment you get. You may get the new treatment or you may get the standard treatment.

- You will likely not know which treatment you are getting until the study is over.

- **Placebos** or sugar pills are almost never used in cancer research studies.

- Putting people in groups at random means that both groups end up with a similar mix of patients. This means that if one group gets better results, it is probably because of the treatment, not who is in the group.
Aim 1: Rural Choices DA Development and Usability Evaluation

- Adults (18+)
- Cancer diagnosis in the past 3 years
- No previous CCT participation
- Rural residing (RUCA $\geq 7.0$)

- 14 interviews completed
  - 28 people were approached; 4 were ineligible
  - 18/28 agreed (68% response rate)
## Demographic Characteristics of Aim 1 Participants (N=14)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Description</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, mean (range)</strong></td>
<td></td>
<td>61.6 (30-73)</td>
</tr>
<tr>
<td>&lt; 65 years, n (%)</td>
<td></td>
<td>6 (42.9%)</td>
</tr>
<tr>
<td>≥ 65 years, n (%)</td>
<td></td>
<td>8 (57.1%)</td>
</tr>
<tr>
<td><strong>Gender, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td>6 (42.9%)</td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td>8 (57.1%)</td>
</tr>
<tr>
<td><strong>Education level, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some high school</td>
<td></td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>High school diploma or GED</td>
<td></td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td>Some college</td>
<td></td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td>College degree</td>
<td></td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td>Graduate or professional degree</td>
<td></td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td><strong>Type of cancer, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td></td>
<td>3 (21.4%)</td>
</tr>
<tr>
<td>Cervical</td>
<td></td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td>Endometrial</td>
<td></td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>Ovarian</td>
<td></td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>Prostate</td>
<td></td>
<td>6 (42.9%)</td>
</tr>
<tr>
<td><strong>Race, n (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian only</td>
<td></td>
<td>14 (100%)</td>
</tr>
<tr>
<td>Hispanic ethnicity: No, n (%)</td>
<td></td>
<td>14 (100%)</td>
</tr>
</tbody>
</table>
Quantitative Results from Aim 1

• Overall positive impression of the tool

• Mean System Usability Scale (SUS) score of 82.9
  • SUS score >68 is considered above average
  • Three participants had below average SUS scores
    • All 3 were men, 60+ years of age
    • All 3 had less than a high school degree
Qualitative Impression of the DA

• “…it’s very helpful and…seems to me all the information that is needed to decide “do I want to participate in a study?” Because each person has to decide for themselves and that gives you the deeper information to make that decision.” (P102, female, breast cancer, ≥ 65 yrs)

• “I think it’s very informative…you know, if I hadn’t had my doctor already explain some of this …this would give me a better overview of what was to come. So I do, I think it was good.” (P115, female, ovarian cancer, ≥ 65 yrs)
Suggestions for Improvement

• “Well I guess, one thing that pops into my mind right away is it doesn’t say…where it would be located for people like us in rural areas, where we gotta travel to. It’s like me coming in here now, it takes me 50 minutes to an hour to get here if there’s no problems with traffic. So people wanna know how far they gotta go to do this.”
  (P112, male, prostate cancer, ≥ 65 yrs)

• “…it would be helpful to have pages like this that broke down different types of cancers and kind of give people pinpoints. Even if it’s other websites that they have found links to take them to, so it was all in one place, easier to find, ‘cause when you’re told you have cancer and you never would expect it, you’re panicked to find information of what to expect…”
  (P101, female, cervical cancer, < 65 yrs)
Aim 2: Pilot the RC-DA among rural-residing cancer patients in a pre-post design

- Feedback from Aim 1 was incorporated into RC-DA
- Evaluate among the target population (N=50)
  - Diagnosed within the past 6 months
  - Rural residing (RUCA > 7.0)
  - Surveys completed before and after tool using RC-DA
  - Outcomes: knowledge about cancer clinical trials, self-efficacy for finding information about trials, certainty about choice, and values clarity
Challenges

• IRB approval from both centers is required
  • We did not want to double consent participants
  • We decided to split the aims by institution
    • WashU will complete Aim 1; SIUSM will complete Aim 2

• Human subjects refresher course
  • Required by SIUSM yearly
  • Not required for WashU employees and does not show up in CITI
  • WashU employees retook the entire course to be SIUSM compliant
Questions

Email:

Mary Politi  mpoliti@wustl.edu
Swati Pathak  spathak57@siumed.edu
Denise Monti  montid@wudosis.wustl.edu
Kathy Robinson  krobinson@siumed.edu
Assessing Head and Neck Cancer Awareness as a Function of Rural Residence: Project Update

Arun Sharma, MD, MS
Assistant Professor, Otolaryngology-Head and Neck Surgery
Southern Illinois University School of Medicine

Lauren D. Arnold, PhD, MPH
Assistant Professor, Epidemiology
Saint Louis University College for Public Health & Social Justice
Background

• Oral cavity and oropharyngeal cancer (OCPC) awareness chosen for this pilot study
• Over 48,000 OCPC cases were diagnosed in 2016\(^1\)
  • 5-year incidence/100,000:\(^2\)
    • US: 11.3
    • Illinois: 11.8
    • Highest incidence in Illinois is in 3 rural counties: 18.0-21.0
• OCPC Risk factors: tobacco and alcohol exposure
  • Rural populations have higher tobacco use\(^3\)
  • HPV implicated in most oropharyngeal cancers\(^4\)
• Knowledge in the general population about OCPC risk factors and symptoms is low\(^5\)
• OCPC knowledge has not been assessed in rural populations

Aims

1. Collect pilot survey data to characterize OCPC knowledge (risk factors, symptoms, screening) and needs among rural residents in Illinois
2. Assess preference for survey modality among rural Illinois residents in preparation for a larger follow-up survey study
3. Conduct interviews to gain in-depth insight to OCPC knowledge, perceptions, and needs among rural Illinois residents
Study Design

• Montgomery County designated as a rural county
• OCPC and tobacco use are prevalent in Montgomery County¹:

<table>
<thead>
<tr>
<th></th>
<th>Illinois</th>
<th>Montgomery County</th>
</tr>
</thead>
<tbody>
<tr>
<td>OCPC incidence (per 100,000)</td>
<td>11.8 (95% CI 11.5-12.0)</td>
<td>18.7 (95% CI 12.9-26.3)</td>
</tr>
<tr>
<td>Prevalence of smoking</td>
<td>16.7% (95% CI 15.2-18.2)</td>
<td>20.9% (95% CI 14.4-29.4)</td>
</tr>
<tr>
<td>Prevalence of chewing tobacco use</td>
<td>3.1% (95% CI 2.5-4.0)</td>
<td>5.3% (95% CI 2.6-10.4)</td>
</tr>
</tbody>
</table>

• Partnership with Montgomery County Cancer Association (MCCA)
  • Longstanding collaborative relationship between MCCA and SIU Simmons Cancer Institute (SCI)
  • MCCA is well known in this community and holds regular social events

• Inclusion Criteria:
  • Age ≥ 20
  • Montgomery County resident
  • English speaking
  • No prior history of cancer (except non-melanomatous skin cancers)

Project Update

• Aim 1: Assess OCPC knowledge among rural residents
  • Survey Development:
    • Based on Humphris Oral Cancer Knowledge Scale and Health Information National Trends Survey (HINTS)
    • 56 items
  • Sections:
    • Demographics
    • Health Insurance: access to medical and dental care
    • OCPC Knowledge/Awareness: risk factors (tobacco, alcohol, HPV), signs, symptoms, role of screening
    • OCPC Screening
    • OCPC Risk Factors
  • Goal sample size: 150
  • Current sample size: 73 (48 female, 25 male)
  • Upcoming MCCA events have been identified for continued recruitment
  • Data entry underway
Project Update

• Aim 2: Assess preference for survey modality
  • Last section of Survey includes items about survey modality preference and sources of medical information
  • Current sample size: 73 (48 female, 25 male)
  • Upcoming MCCA events have been identified for continued recruitment
  • Data entry underway
Project Update

• Aim 3: Conduct interviews to gain in-depth insight
  • Goal sample size: 20
  • 15 participants agreed to be interviewed 1:1 by research coordinator
  • Health Belief Model will guide interviewers:
    • Perceived susceptibility to OCPC
    • Severity of OCPC
    • Access to medical and dental care
    • Willingness to change lifestyle
    • Preference for intervention strategies
    • Barriers to making changes
  • Research coordinators are scheduling interviews
  • Research coordinators have been trained in performing interviews
  • Final mock interviews will be performed with co-investigators prior to actual interviews
Questions? Comments?

• Acknowledgements:
  • Kathy Robinson, PhD
  • Meera Muthukrishnan, MPH
  • Whitney Zahnd, MS
• Research coordinators:
  • Candace Griffith
  • Ali Davis
  • Rebecca Wolf
• Montgomery County Cancer Association (MCCA)
Southern Illinois Cancer Related Resources: Collaborating to Improve Health Outcomes in Southern Illinois

Woody Thorne, MSEd, Vice President, Community Affairs
Angie Bailey, MPH, MSEd, CHES, Community Benefits Manager
Southern Illinois Healthcare
Cancer
with a focus on breast, colorectal and lung cancer

GOAL: Reduce the death rates for female breast cancer, colorectal cancer and lung cancer in Franklin, Jackson, Johnson, Perry, Saline, Union and Williamson Counties.

The Local Problem

Cancer is the second leading cause of death in the SIH seven county service area.

Cancers of Most Concern in the SIH Seven County Area

- Breast Cancer
- Colorectal Cancer
- Lung Cancer

Data Sources
1. IDPH, Causes of Death by Resident County, 2012
2. NIH, National Cancer Institute, State Cancer Profile, Age-Adjusted Incidents by Cancer Site 2007-2011
3. Illinois County Behavioral Risk Factor Surveys, Fifth Round; 2010-2011; Illinois Department of Public Health
**Cardiovascular Disease**
and its contributing risk factors of diabetes and obesity

GOAL: Increase cardiovascular health among children and adults in Franklin, Jackson, Johnson, Perry, Saline, Union and Williamson counties.**

---

**The Local Problem**

67.6% of Adults are Overweight or Obese

<table>
<thead>
<tr>
<th>% of Population Not Meeting Recommended Daily Fruit and Vegetable Intake</th>
<th>% of Adults Living With Diabetes</th>
<th>% of Adult Smokers</th>
</tr>
</thead>
<tbody>
<tr>
<td>80%</td>
<td>7.8%</td>
<td>26.8%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>% Living in Areas Designated as Food Deserts</th>
<th>% of Medicare Patients Ages 65 &amp; Older Are Being Treated for Diabetes</th>
<th>% of Adults Who Reported Not Participating in Any Physical Activity in the Last 30 Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>25.11%</td>
<td>26%</td>
<td>19.6%</td>
</tr>
</tbody>
</table>

---

**Data Sources**

1. IDPH, Causes of Death by Resident County, 2012
Hotspot #1: Lower Mississippi Delta

• 94-county area spanning:
  • Mississippi (27 counties)
  • Arkansas (17)
  • Illinois (16)
  • Missouri (15)
  • Tennessee (10)
  • Louisiana (6)
  • Kentucky (3)

• Demographics:
  • 61% white and 37% black (2009-2011)
  • Ranked as persistently poor (≥20% poverty) since 1970
  • ~22% of all MS Delta residents uninsured in 2009

• CRC screening uptake in all involved states are below national median (64.5%), with Mississippi (57.1%) and Arkansas (58.6%) ranking in the lowest quartile of all 50 states.
SIH Cancer Institute

• BJC Collaboration – Siteman Regional Cancer Task Force

• Multidisciplinary site specific groups

• Cutting edge technology and treatments
## 2015 New Cancer Cases

<table>
<thead>
<tr>
<th>Year</th>
<th>Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>865</td>
</tr>
<tr>
<td>2012</td>
<td>866</td>
</tr>
<tr>
<td>2013</td>
<td>971</td>
</tr>
<tr>
<td>2014</td>
<td>974</td>
</tr>
<tr>
<td>2015</td>
<td>1224</td>
</tr>
</tbody>
</table>

- **Lung** 225
- **Breast** 213
- **Digestive System** 152
- **Urinary** 106
- **Prostate** 83
- **Lymphatic Blood** 39
Walking path and view of the infusion center
Due to growth in volumes we are adding 6 additional infusion chairs to the space. Bringing total to 27 chairs.
Bringing care close to home for those living in southern Illinois.

<table>
<thead>
<tr>
<th>Service</th>
<th>Actual miles traveled 26 miles from home</th>
<th>Miles if treated in St. Louis 108 miles from home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery &amp; Follow up</td>
<td>4 visits?</td>
<td>208</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>12 visits</td>
<td>552</td>
</tr>
<tr>
<td>Radiation Therapy</td>
<td>33 visits</td>
<td>1518</td>
</tr>
<tr>
<td>Cancer Rehab</td>
<td>8 visits</td>
<td>368</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2646</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12312</td>
</tr>
</tbody>
</table>

Grand lobby offering a welcoming environment where our focus was bring nature – creating a calming healing center.
• The Coach Kill Fund has a mission of improving the quality of life for individuals and families facing a financial burden resulting from the medical treatment of cancer and other health conditions.

• The SIH Foundation is the charitable arm of Southern Illinois Healthcare (SIH) and was established in 2010 to receive philanthropic gifts on behalf of Herrin Hospital, Memorial Hospital of Carbondale and St. Joseph Memorial Hospital of Murphysboro.
• **Strong Survivors** is a free, 12 week program to help cancer patients and survivors develop an exercise routine and make good, proactive choices about nutrition.

• **4 Main Goals:**
  – Help you learn good nutrition and physical activity
  – Regular exercise under the supervision of a Cancer Exercise Specialist
  – Improve your quality of life as a cancer survivor
  – Have fun

• **Who is Eligible?**
  – Any person who has experienced cancer and one “caregiver.”
Healthy Southern Illinois Delta Network

Transforming Southern Illinois into a region that supports and enhances healthy living since 2008

HSIDN represents the southernmost 15 counties of Illinois.

Making the Healthy Choice the Easy Choice

www.hsidn.org
FOCUS OF PROGRAMMING

- Increased Physical Activity
- Improved Nutrition
- Smoke Free Public Places
- Chronic Disease Prevention & Management

SOUTHERN ILLINOIS HEALTHCARE

SIU School of Medicine - Center for Rural Health and Social Service Development
The HSIDN’s goal...

- To serve as a catalyst for improving health and quality of life in southern Illinois by...
  - Building infrastructure for making changes—county coalition and regional network
  - Engaging policy makers and partners
  - Improving health equity through a policy, systems, and environmental approach
Healthy Communities Coalition Connects Community Sectors

- Churches
- Schools
  - Primary/Secondary
  - Higher Education
- Health Care Systems
- Local Health Departments
- Government
- Service Agencies
- Business Leaders
PSE Changes in the Region

- More Walking and Biking Paths
- Coordinated School Health Programs
- Community and School Gardens
- Shop Healthy Southern Illinois/Farmers Markets
- Smoke Free Worksites, sports fields and Playgrounds
- Smoke-free housing efforts
- Healthcare Provider training
- Diabetes Today Resource Teams
- Southern Illinois Cancer Action Team and much more
Lung Cancer Mini-Reports

The Healthy Southern Illinois Delta Network (HSIDN) serves as a catalyst for improving the health and quality of life in southern Illinois. The HSIDN consists of seven community coalitions directed by steering committees representing the seven health departments within the southernmost 16 counties in Illinois. These seven coalitions include Hamilton County Health (HCHC), Randolph County All Health (RCAHC), Healthy Southern Seven (H7SC), Southeastern Illinois Community Health (SICHC), Jackson County Healthy Communities (JCHCC), Perry County Health & Wellness (PCHWC), and Franklin Williamshus Healthy Communities (FWHCC). Occurrence and death rates from lung cancer are higher in southern Illinois compared to other parts of the state. The HSIDN is a collaborative effort to improve health and lower the lung cancer death rate.

Cancer Occurrence and Death Rates

In 2012, 552 new lung cancers were diagnosed in Healthy Southern Illinois.

---

Southern Illinois Cancer Risk Factor Report

Lung cancer is the leading cause of cancer death in the United States. More than half of the people who die of lung cancer will die within a year of being diagnosed. The leading risk factor for lung cancer is smoking. The Perry County Health and Wellness Coalition (PCHWC) is a member of the Healthy Southern Illinois Delta Network (HSIDN) coalition that serves as a catalyst for improving the health and quality of life in southern Illinois. Occurrence and death rates from lung cancer are higher in southern Illinois compared to other parts of the state. The HSIDN is a collaborative effort to improve health and lower the lung cancer death rate.

Over the last ten years, 66 friends and family members residing in Perry County have died from lung cancer. In 2013, 20 new lung cancer cases are anticipated in the PCHWC area.

Preventing Lung Cancer

Nationally, 80-90% of lung cancer cases are due to smoking.^

- Illinois has seen a 1.4% annual decrease in lung cancer mortality since 2000.
- The best way to prevent lung cancer is to avoid smoking.
- Workplaces and other public health/wellness programs for employees to help reduce smoking.
Partners Include:
• American Cancer Society
• Southern Illinois Healthcare
• Local Health Departments
• SIU School of Medicine
• Federally Qualified Health Centers
• And many others.

Contact Information:
Angie Bailey
Community Benefits Manager
Southern Illinois Healthcare
(618) 457-5200, ext. 67834
angie.bailey@sih.net

Caleb Nehring
Health Systems Manager
American Cancer Society
(618) 990-9258
caleb.nehring@cancer.org

For more information visit
www.hsiod.org

Cancer
Action Team
Jackson County
Healthy Communities Coalition

Overall Goal
• Enhance preventive behavior and survivorship surrounding colon, prostate, breast and cervical cancer in Jackson County.

Strategies
Increase the screening rates for colon, prostate, breast and cervical cancer:
• Through the implementation of various evidence-based interventions.
• By developing and promoting toolkits and training for healthcare providers/clinicians to aid in screening compliance and patient education.

Working Together To Create A Healthier Jackson County
Southern Illinois Cancer Action Team

SAVE THE DATE
The Illinois Cancer Partnership Invites You to the Inaugural
Southern Illinois Colorectal Cancer Collaborative Meeting
Tuesday, September 22, 2015, 10:00 AM to 2:00 PM
SIU School of Medicine’s Center for Rural Health and Social Service Development
1745 Innovation Drive
Carbondale, IL

Sixteen counties in Southern Illinois have been identified as being located in one of the “Top 3 Hot Spots” in the nation with the highest colorectal cancer death rate. The Illinois Cancer Partnership, in cooperation with the American Cancer Society – Lake Shore Division, has joined a group of area providers, clinicians, public health professionals and other members for a common goal – to lower the incidence and mortality of colorectal cancer in Southern Illinois.

DATE | TWITTER
--- | ---
January 1 | It's January, and January is Cervical Health Awareness month! Read more: [http://go.sph.iit.edu/1](http://go.sph.iit.edu/1)
Week 1 January 3 | The cervix is part of the female reproductive structures. It connects the vagina and uterus. Cancer of the cervix is called Cervical Cancer. [http://go.sph.iit.edu/2](http://go.sph.iit.edu/2)
FOR MORE INFORMATION:
Healthy Southern Illinois Delta Network
www.hsidn.org

OUR STORY

The Healthy Southern Illinois Delta Network (HSIDN) is a grassroots effort established to build consensus around the health needs of residents in southernmost Illinois.

The Network brings together local health departments, area health centers, hospitals and others interested in improving the health of their communities. Members work together to support healthy communities in the lower fifteen counties in Illinois.

HSIDN members include Southern Illinois Healthcare, the Center for Rural Health and Social Service Development and the area’s six health departments covering a fifteen county region. Regional efforts are coordinated by the steering committee and implemented at the local level through healthy community coalitions. Coalition members and action teams engage their own communities to conduct activities and advance the overall mission of the HSIDN.

The Network has grown into a strong collaborative effort of community organizations successfully leveraging resources to improve health in the Illinois delta region. The success of the network is a direct result of the regional planning approach supported by active engagement of those representatives interested in improving the health of their communities. This collective effort is supported and facilitated by Southern Illinois Healthcare, a non-profit hospital system with the support of SIU School of Medicine.
Delta School Health Grant

HRSA

SIU SOM CRHSSD

Southern Illinois Healthcare

Egyptian Health Department

Franklin Williamson Bi-Co. Health Dept

Jackson County Health Dept.

Southern Seven Health Department
Illinois CATCH on to Health Consortium!

- SIU School of Medicine Center for Rural Health & Social Service Development
- Southern Illinois Healthcare
- Franklin-Williamson Bi-County Health Dept.
- Jackson County Health Department
- Perry County Health Department
- University of Illinois Extension
- Egyptian Health Department
- Southern 7 Health Department
- JALC – Child Care Resource and Referral
- Centerstone
- And many others.....
Working Together to Improve Southern Illinois

- Together, ICHC impacts over 80 schools and 20,000 kids in the lower 16 counties of Illinois.
WHOLE SCHOOL.
WHOLE COMMUNITY.
WHOLE CHILD.
Classroom Curriculum

Physical Education

Child Nutrition

Family
Faith Community Efforts

- Each Health Ministry team plans a program that meets the needs and resources of their own faith community.
- SIH Health Ministry is a resource to 50+ congregations and faith based agencies in nine counties.
- Over 150 nurses have completed Foundations of Faith Community Nursing/Parish Nursing Course since 1999.
Congregational Health Connectors

- Lay members who receive training to promote healthier lifestyles within the congregation and community.
- Learn to identify people who are at risk for health problems.
- Assist with planning health events or programs that can benefit the whole congregation.

The Model for Healthy Living
None of us can do it alone!