Influencing cervical cancer prevention and detection online through social media

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Roadmap

- Brief introduction/ career trajectory
- R01 NCI SNOWBALL project on the influence of social media on cervical cancer prevention and control
- Directions for future research
Who I am

- Primary care physician+investigator
- Transforming health systems and health communication to improve the safety and quality of care for diverse populations
  - Follow-up of abnormal tests
  - Missed and delayed diagnosis
  - Adverse drug events
  - Health system innovations
- Intersection between technology, digital health, and cancer prevention and control
Influencing cervical cancer prevention and detection online through social media

National Cancer Institute R01CA178875 (Co-PIs: Sarkar & Centola)
Study Goal

Use a mixed-methods approach to online social media and social networks for enhancing understanding of cervical cancer screening to optimize the spread of health messages and behaviors within online social networks.
SNOWBALL Team

Multi-disciplinary Team:

- **Urmimala Sarkar, MD, MPH**: Lead PI
- **Damon Centola, PhD** (UPenn): Co-PI, sociologist, social networking research
- Byron Wallace, PhD (UT Austin): computer scientist, machine learning methods
- George Sawaya, MD: obstetrics/gynecology, cervical cancer expertise
- Rena Pasick, DrPH: behavioral and qualitative research
- Courtney Lyles, PhD: health services research
- Gem Le, PhD, MHS: project manager, social epidemiology, cancer prevention
Specific Aims

**Aim 1**: To use machine learning techniques (i.e., large-scale computer algorithms) to identify and rank the key words related to cervical cancer screening and HPV vaccination in social media messages.

**Aim 2**: To categorize and validate the range of cervical cancer screening and HPV vaccination discussion on social media.

**Aim 3**: To create cervical cancer screening and HPV vaccination messages for social media and evaluate their effectiveness for increasing diffusion through online social networks.
Cervical Cancer Epidemiology

- 12,109 new cases of cervical cancer per year\(^1\)
- Disparities by race/ethnicity/education\(^1\)
  - Hispanic women have highest rates
  - Women with < high school education have lowest rates of screening
- 19% of adolescent girls (ages 12-17) and 11% (ages 18-27) initiated HPV vaccination in 2007\(^2\)
- Ongoing need to bolster screening and prevention efforts

What is Social Media?

- “Social media are Web-based tools that are used for computer-mediated communication.” (Grajales, JMIR, 2014)
- Interactive, user-generated content
- Key method for communication
Why use social media for research?

Applications to health include:

- Promoting public health campaigns
- Reporting real-time trends for infections
- Recruitment of patients to online studies and clinical trials
- “Contagion” of behavior via social media


What is Twitter?

- Microblog = platform for information dissemination, social networking, and real-time communication.
- Allows networks of users to send short updates to each other in less than 140 characters.
- Messages on Twitter are called “tweets”
Sample Tweet

Francis S. Collins @NIHDirector · Jul 5

I will request my health records & share that experience. Need #GetMyHealthData #DataIndependenceDay to work for #pminetwork to succeed

6:07 AM · 5 Jul 2015 · Details
Sample Tweet

National Cancer Inst @theNCI · Jul 17
NCI’s National Clinical Trials Network enrolled 19,000 patients in clinical trials in 2014: 1.usa.gov/1fbyoDG
Tweeting about Pap Smears

- “5 minutes of uncomfyness is better than cancer 4 a lifetime”

- “Guys encourage your mothers, sisters, wives, and girlfriends 13 to have regular pap smear. Also encourage them to get the vaccine.”

- “Took the afternoon off so I could get a pap smear and my car could get an oil change. :-/”

SNOWBALL Data & Methods

Aim 1 work:

- 119,428,139 Twitter messages obtained from March 2014 (1% sample from all of Twitter)
- Filtered messages matching our keywords of interest (e.g., pap smear, HPV, papillomavirus, pap test, cervical, cervix, cervical cancer, papanicolau, squamous, smear test, dysplasia)
- Applied Sparse Principal Components Analysis (SPCA) to identify clusters of keywords that are mathematically grouped into topics
A selected automated “topic”

1. CBC News HPV Vaccine Funding Cut by Canadian Province; polyDNA Recommends that Canadian Doctors Learn About… http://t.co/QSn8Urev73
2. RT @gogreen18: the anti-vaccine movement scares the crap out of me. i have paranoid family members now opting out of HPV vaccines for their kids.
3. Study: HPV vaccine working - The Human Papillomavirus vaccine has reduced the frequency of abnormal Pap smears and…http://t.co/X7bF0l8sYW
4. @positivegp is HPV vaccine only for girls/women? The lady mentioned genital warts on the penis as well, do men get vaccine?
5. Another Success for HPV Vaccine http://t.co/DEgyZlYyFb
6. @CherylMHolmes on province set to stop funding HPV vaccine for some women: http://t.co/QVEjwlpSYB
7. RT @CherylMHolmes: Manitoba to cut free HPV vaccine program for young women on April 1. Are you worried about getting your shots?
8. #googlenews One dose of HPV vaccine may prevent cervical cancer - New Straits Times http://t.co/StYww0Cijl
9. RT @Rwanda_Post: Vaccine for Cervical Cancer Coming to Rwanda - http://t.co/sLWCpoqWLe #Rwanda #RWoT
10. @RTH2039: BMJ Press Release:HPV vaccine provides significant protection against cervical abnormalities http://t.co/t1nWLulGzP @JulieLeask
Next steps

- Aim 2 work focused on qualitative analysis
- Qualitatively code a large purposive sample of social media content (minimum 1500 messages) collected under Aim 1
- Synthesize data from Aims 1 and 2 to develop social media messages for testing in Aim 3 (e.g., identifying key influencers from Aim 1 (individuals vs. organizations), addressing misconceptions/cancer myths observed from Aim 2)
- Develop study protocol for Aim 3 in detail; online social network experiment to go live in Summer 2016
Advantages of using social media

- Provides **immediate, real-time data**
- Minimal observation bias
- Provides insights into health behaviors that are not usually shared in traditional methods of public health data collection

“Behaviors that people might be reluctant to share with physicians are on full display on Twitter, including behaviors, opinions, and subpopulations that are otherwise difficult to track through traditional mechanisms, suggesting a whole new area of large-scale public-health research.” (Dredze, 2012)

Caveats in analyzing social media data

- Socio-demographic characteristics
- Subject to selection bias
- Twitter users more likely to be young and non-white
Caveats in analyzing social media data

- **Social media data viewed as MORE than “big data”**
  - Big data refer to very large datasets that can be analyzed or mined quantitatively to explore human behaviors and interactions.
  - Analysis of social media data need to incorporate mixed methods.
    - Should **not** rely on automated analysis alone (e.g., machine learning methods) for meaning analysis and interpretation of the data.
Directions for future research

- Follow-on to online social network experiment to develop social media messaging for other screenable cancers
- Integrating mHealth data with online social networks
- Recruit specific patient populations to online social networks
  - Observe peer support, decision-making for cancer treatment
  - Opportunities for researching hard-to-reach populations (e.g., minority youth)
- Mixed-method approaches to analyzing online social network data
  - Potential: online disease communities
Thank you

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Urmimala.Sarkar@ucsf.edu
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CFIR Construct Definitions
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<td>CBC News HPV Vaccine Funding Cut by Canadian Province: polyDNA Recommends that Canadian Doctors Learn About... <a href="http://t.co/QSN8Urew73">http://t.co/QSN8Urew73</a></td>
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