The social media impact on patient and public perspectives

Presented by:

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Speaker disclosure

• I do not have an affiliation (financial or otherwise) with a pharmaceutical, medical device or communications organization.
• I do not intend to make therapeutic recommendations for medications that have not received regulatory approval (i.e. “off-label” use of medication).
Presentation disclosure

- No financial or in-kind support was received from a commercial organization to develop this presentation
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Mitigating potential bias

The planning committee for this conference has reviewed all available presentations to be given at the conference to ensure the scientific validity and objectivity of the content and therefore has deemed there to be little potential for bias or conflict of interest in relation to the speaker(s) declaration(s) and the event content.
Learning objectives

After this session, participants will:

- be able to identify the functional characteristics and corresponding issues related to different types of social media sites
- be able to review, interpret, and evaluate social media research projects in science and health related contexts
- be able to assess how social media might be influencing their particular field
- plan and develop strategies to tackle social media issues as they apply to their particular contexts
Organization of the workshop

1) What are social media?
   ➢ Definitions
   ➢ Most popular types and some characteristics
   ➢ Benefits and issues

2) Social media research in the health context
   ➢ Influence and use
   ➢ Clusters and communities
   ➢ Examples

3) Suggestions, ideas and discussions
   ➢ Which actions can be taken?
   ➢ What lies ahead
This short workshop

- Lots of studies and data
- A few stories and anecdotes
- Some participation from you
What is “social media”?

A story about the INTERNET!... and ICQ
What are social media?

“Internet-based tools that allow individuals and communities to gather and communicate; to share information, ideas, personal messages, images, and other content; and, in some cases, to collaborate with other users in real time. Social media are also referred to as “Web 2.0” or “social networking.”

- Interactional logistics that both *enable* and *restrict*
- Platform control (top-down) and user control (bottom-up)
- Communication ecosystems
Who is using social media?

- Almost everyone...in some capacity.
- Over 2 billion people use Facebook (25% of the world)
- Canadian stats on adults:
How are social media used?

Social media creates dynamic interactive networks for...

Social networking.

Professional networking.

Sharing media.

Producing content.

Social play.

Professional play.
Social media creates dynamic interactive networks for...

- Raising funds.
- Making profits.
- Knowledge/Information aggregation.
- Building communities of support.
- Virtual reality creation for play and education.
- Waging communication wars.

Second Life VR

Donald J. Trump @realDonaldTrump

My use of social media is not Presidential - it's MODERN DAY PRESIDENTIAL. Make America Great Again!

5:41 PM - 1 Jul 2017

#WCCME
Popular social media sites in China

WeChat
Similar to Facebook but with purchasing food, services, products, etc.

Weibo
Similar to Twitter

Douban
Entertainment-based site mixing sites similar to IMDB, reddit and Spotify
Social Media: Key characteristics, quirks and concerns:

- Data (management, control, privacy, profits, advertising, obsessive tracking...)
- Algorithms (The computational rules governing or managing the interactions in the particular ecosystem) *the goal is to increase interactions*
- Authenticity (Bots and “fake news”)
- THE BIG Q... Influence: How are we and our environments affected?
Authenticity (Bots and “fake news”)

Bots – Internet robots that perform automated tasks (Fake accounts that “like” and “share”)

- Prominent on Twitter (approx. a minimum of 10%)
- Fun, interesting, dangerous...

Taken from: http://www.newnationalist.net/2017/02/13/fbi-insider-exclusive-california-pizzagate-pedo-rings-under-investigation-hollywoodnapa-valley-and-more/
World Worried About Fake News as a Weapon

Nearly 7 in 10 worry about false information or fake news being used as a weapon

Source: 2018 Edelman Trust Barometer, ATT_MED_AGFR. Below is a list of statements. For each one, please rate how much you agree or disagree with that statement using a nine-point scale where one means "strongly disagree" and nine means "strongly agree". (Top 4 Box, Agree), question asked of half of the sample. General population, 26-market global total.
Authenticity (Bots and “fake news”)

New methods are being developed and experimented with to combat it.

http://www.fakenewschallenge.org/

http://www.opensources.co/

https://www.snopes.com/
Influence and Impact: Theories, cases and studies

- Concerns of Echo Chamber, Personalization, or My Net
- The idea of “Homophily”

“Similarity breeds connection...personal networks are homogeneous with regard to many sociodemographic, behavioral, and intrapersonal characteristics. Homophily limits people's social worlds in a way that has powerful implications for the information they receive, the attitudes they form, and the interactions they experience. Homophily in race and ethnicity creates the strongest divides in our personal environments, with age, religion, education, occupation, and gender following in roughly that order.”

Miller McPherson 1, Lyman Smith-Lovin 1, and James M. Cook 1,2

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2Department of Sociology, Duke University, Durham, North Carolina 27708; e-mail: jcook@soc.duke.edu
Concerns of Echo Chambers and Internet Personalization

- Like-minded people are speaking predominantly to one another (“liking” and “sharing”)

- New – and correct! – information is not being seen...or constructively taken into account

- People are not being exposed to diverse viewpoints

- Social media and internet technologies are exacerbating this dynamic

- Idea proponents: Eli Pariser, creator of Upworthy, and Harvard Law professor Cass Sunstein, author #republic

Evidence and explanations of echo chambers and polarization

Assassination of late-term abortion doctor George Tiller spurred PRO CHOICE vs PRO LIFE debates

“...replies between like-minded individuals strengthen group identity, whereas replies between different-minded individuals reinforce in-group and out-group affiliation. Their results show that people are exposed to broader viewpoints than they were before but are limited in their ability to engage in meaningful discussion.”

Echo chambers in the age of misinformation
Additional considerations for how perspectives are formed

- **Intensified polarization** – polarization of opinions often becomes stronger after deliberation and interaction with opposing perspectives\(^6\)

- **Biases and reasoning** – social and emotional factors impact reasoning – at times overriding rationality (\textit{Confirmation Bias, Information Avoidance}, etc.)\(^7, 8, 9\)

- **Group dynamics** (In-group vs out-group) – allegiance to one’s group and identity; the role of influencers

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\(^6\) Carnegie Mellon University

[March 13, 2017]

Information Avoidance: How People Select Their Own Reality

By Shilo Rea

Influencers impact how people come to think about certain topics and how those perspectives are maintained.
Socio-political influences (Building camps of perspectives and trust)

“Public intellectuals”
Antonio Gramsci

Image taken from: https://en.wikipedia.org/wiki/Antonio_Gramsci

#vaccineswork

Discourse Coalitions (Hajer 1993)

“A discourse coalition is the ensemble of a set of story lines, the actors that utters these story lines, and the practices that conform to these story lines, all organized around a discourse.” (Hajer 1993: 47).

#bigpharma
Peers Are Now as Credible as Experts

Percent who rate each spokesperson as extremely/very credible 2016 vs. 2017

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<th>2017</th>
<th>Government official</th>
<th>Board of directors</th>
<th>CEO</th>
<th>NGO rep</th>
<th>Financial industry analyst</th>
<th>Employee</th>
<th>A person like you</th>
<th>Academic expert</th>
<th>Technical expert</th>
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Image taken from: https://www.ickollectif.com/single-post/2017/01/16/Peers-as-credible-as-experts-and-more-than-CEOs
To Your Health

No, Gwyneth Paltrow, women should not put jade eggs in their vaginas, gynecologist says

Herd Influence:

Content that is automatically “liked” is 32% more likely to get another like.
Using actual fake news headlines presented as they were seen on Facebook, we show that even a single exposure increases subsequent perceptions of accuracy, both within the same session and after a week – that is, an illusory truth effect exists for fake news. Moreover, increased perceptions of accuracy for repeated fake news headlines occurs even when the stories are labeled as contested by fact checkers, or are inconsistent with the reader’s political ideology. These results suggest that social media platforms help to incubate blatantly false news stories.”16
In large numbers, people are going online for health information all over the world, using search engines and social media\textsuperscript{10,11,12,13,14,15}

- Self-diagnosing
- Getting second opinions after visiting with doctors / Verifying previously-obtained information
- Looking up treatments and alternative treatments
- Visiting online health communities to learn and discuss
- Researching hospitals and health-care practitioners

Health services also have an increasingly large presence
- In the US, 95% of hospitals are on Facebook and 50% are on Twitter\textsuperscript{10}

People in the US are becoming open to sharing personal health information online
- 80% of individuals aged 18-24 said they would likely share health information on social media compared to 45% of adults 45-64\textsuperscript{12}

Increase in all kinds of apps and wearable technology

Health Online
Many Americans belong to online patient health groups like “PatientsLikeMe”, and many report numerous benefits from joining such groups

- In 2015, PatientsLikeMe had 250,000 unique users with over 2,000 conditions\textsuperscript{13}
- The parent group Mumsnet generates around 4.8 million monthly visitors primarily discussing breastfeeding and miscarriage\textsuperscript{13}
- My Pro Ana – a pro-anorexia online community – had some 115,000 members in 2014\textsuperscript{13}

**Reported Benefits**

- Learning new information\textsuperscript{10,11,12,13}
- Connecting with other individuals (getting support and sharing experiences)\textsuperscript{10,11,12,13}

On PatientsLikeMe - 30% of Epilepsy patients did not know someone with epilepsy prior to using the site\textsuperscript{12}

- Building trust (more learned peer experts become authority figures)\textsuperscript{11,12}
- Overcoming social stigma\textsuperscript{11,13}
- Helps cope with some depression\textsuperscript{12}
Information quality?

On one hand...  ... but on the other hand

So.... what are the impacts?
A wide, wide range...
The **American Academy of Facial Plastic and Reconstructive Surgeons** has noticed the trend too. According to a 2017 poll, 55 percent of facial plastic surgeons reported seeing patients who wanted surgeries to help them look better in selfies, up from 13 percent in 2016.

General influence:

• 45% of consumers said information found via social media would affect their decisions to seek a second opinion

• More than 40% said that information found via social media would affect the way they coped with a chronic condition or their approach to diet and exercise

• Approximately 33% said that social media would affect their decisions regarding taking certain medications and undergoing specific procedures or tests\(^{12}\)
WHOA HORSEY!
Research: Topic #1: “Alternative” therapies (CAM) – Chiropractic

Q: What presence do critical voices of Chiropractic have on Twitter?
A: Scant. Very Scant. AND BOTS!
Q: Are people debating Chiropractic’s benefits or risks on popular chiropractic YouTube videos? If so, how are they doing so?

A: Yes, they are.

Diverse methods of argumentation. Some constructive discourse.
Topic #2 – Stem cell therapies

Gordie Howe’s “Miraculous Treatment”: Case Study of Twitter Users’ Reactions to a Sport Celebrity’s Stem Cell Treatment

Monitoring Editor: Gunther Eysenbach
Reviewed by John Rasko, Margaret Ozan-Rafferty, and Julie Robillard
Li Du, MB, PhD, Christen Rachul, MA (ApplIng), Zhaocen Guo, M.Sc. (Tech.), and Timothy Caulfield, LL.M.

Results

78.87% (2195/2783) of tweets mentioned improvements to Howe’s health. Only one tweet explicitly mentioned that Howe’s SC treatment was unproven, and 3 tweets warned that direct-to-consumer SC treatments lacked scientific evidence. In addition, 10.31% (287/2783) of tweets mentioned challenges with SC treatment that have been raised by scientists and researchers, and 3.70% (103/2783) of tweets either defined Howe as a “stem cell tourist” or claimed that his treatment was part of “stem cell tourism”. In general, 71.79% (1998/2783) of tweets portrayed a positive attitude towards Howe’s SC treatment.
Topic #2 – Stem cell therapies

Highly extreme representation of the science around stem cell therapies: Both hyperbolic cures and fears
Topic #3: Vaccines – Distinguishing clusters of communities and rhetoric

“It is common for the vaccinating mainstream to present vaccine hesitant and rejecting parents as a group subject to epistemic closure, groupthink, confirmation bias and over-confidence in their own expertise. However, vaccine hesitant and rejecting parents also see mainstream society as a group—a much larger one-subject to the same problems. We suggest the need to mitigate the 'groupness' of vaccination and non-vaccination by extending the practice of vaccination to recognisable practitioners of holistic health.”

“...provaccine websites analyzed concentrate on the accurate transmission of evidence-based scientific research about vaccines and government-endorsed vaccination-related practices, whereas the vaccine-skeptical websites focus on creating communities of people affected by vaccines and vaccine-related practices.”
Topic #3: Vaccines – Distinguishing clusters of communities and rhetoric

“Of the 330 naturopath websites we analysed, 40 included vaccine hesitancy discourse and 26 offered vaccine or flu shot alternatives....

We concluded that tightening advertising law, reducing CAM practitioners’ ability to self-regulate, and improving enforcement of existing common and criminal law standards would help limit naturopaths’ ability to spread inaccurate and science-free anti-vaccination and vaccine-hesitant perspectives.”

In the image, there is a citation for an article from the Journal of Law and the Biosciences by Timothy Caulfield, Alessandro R Marcon, and Blake Murdoch. The citation is as follows:

Injecting doubt: responding to the naturopathic anti-vaccination rhetoric

Timothy Caulfield®, Alessandro R Marcon, Blake Murdoch

Journal of Law and the Biosciences, Volume 4, Issue 2, 1 August 2017, Pages 229–249,
https://doi.org/10.1093/jlb/lsx017
Published: 20 June 2017

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The Society of Obstetricians and Gynaecologists of Canada

#WCCME
Distinguishing clusters of communities and rhetoric

Wellness culture and wellness industry // The power of Twitter

Sources:

#WCCME
The curious case of GMOs, climate change and selective science
Communicative and culture clustering, information and misinformation, greater truth (?)

Spreading of fake Ebola treatments on Twitter in Nigeria

Forums and hashtags promoting anorexia and eating disorders

NIPT discussions on reddit

Rapid spreading of negative HPV vaccine information on YouTube
Research challenges and what makes/will make good research:

- Difficult to build datasets (More work is needed on Facebook, Instagram, and other sites like reddit)
  
  [Forthcoming work on breastfeeding images on Instagram with Dr. Azad in Winnipeg]

- Privacy is an issue

- More intensive work on interactions inside the data

- Research needs to examine a social health phenomena across various applications and using mixed-methods

- Continual and increased focus on context (acknowledging science, health science, social sciences, culture...)

- Interdisciplinary efforts especially involving computer scientists
A story of a recent injury...
Some idea & suggestions:

➢ Be aware...

  • People ARE GOING ONLINE and get information
    • Of different clustered communities with varying beliefs and perspectives
      • Of rhetoric used
    • Of the speed and power of social media
      • Of what’s trending

➢ Be active and be involved...

  • In engaging – or supporting the engagement of – public education
    • In building trust
    • In defending truth
Thanks to all of our incredible team at the University of Alberta’s Health Law Institute:

Timothy Caulfield, Robyn Hyde-Lay, Blake Murdoch, Candice Kozak

– and many ongoing collaborators who are still part of our team (Meaghan Toews, Ubaka Ogbogu, Christen Rachul, Zubin Master...)

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Footnoted References