Social Media and Infectious Diseases

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Objectives

1) To understand the impact of social media on disease transmission
2) To understand social media in the control of infectious diseases
3) To advocate for clinician involvement in social media for disease awareness and prevention

Conflict of Interest

Financial Disclosures
None

Unlabelled/Unapproved Use Disclosures
None

Other Disclosures - I am an active user of social media

16 years ago

What is social media?

forms of electronic communication (as Web sites for social networking and microblogging) through which users create online communities to share information, ideas, personal messages, and other content (as videos)

Term first coined in 2004

Merriam-Webster's Dictionary
The development of social media

Initially emails sent between computers in 1971
Followed by messaging boards in late 70's
Self-created websites in 1994 (Geocities)
Instant messaging in late 90's
Friendster, myspace, and facebook in 2003-2005

www.onlineschools.org

Social media are a catalyst for the advancement of everyone’s rights. It’s where we’re reminded that we’re all human and all equal. It’s where people can find and fight for a cause, global or local, popular or specialized, even when there are hundreds of miles between them.

Queen Rania of Jordan

Why infectious diseases?

Social media links people, and they may be worlds apart or in the next room
Can be used as a gateway to meet people online and in reality with similar interests
Conversely, can bring together people who would have never met in real life
Everyone can access, in the poorest most remote settings
The data people generate from social media can be correlated to surveillance

Case 1: The rise of Infectious Diseases

First outbreak

Early Syphilis in Southern California in 1990's was fairly rare (41 cases)
All of a sudden an increase in cases described in 2000-2002, particularly in MSM
A significant number of cases had been in HIV(+)
Clinically relevant as syphilis in HIV can be a cause of morbidity (early CNS disease, end organ complications, increase transmission, difficulty in treatment)

Centers for Disease Control and Prevention (CDC) indicates and early syphilis infection among men who have sex with men (MSM)
First outbreak

Epidemiological investigation into cases in 2000
2 men with early syphilis admitted to a number of contacts who met through an AOL chat group

How do you do contact screening through the internet?

First outbreak

Initially local public health asked for disclosure from ISP, but turned down due to privacy reasons

Referred to a marketing firm, specialized in Internet resources for MSM —— Campaign to encourage prevention / testing

Public health sent messages to at-risk individuals through AOL

High risk internet behaviour

Denver study (n=866) self reports through an STI clinic in 2000
15.8% looked for a partner over the Internet, and nearly 2/3 had sex with an Internet partner

Those who had Internet relationships tended to be male, MSM

Had more previous STD's, more partners, more partners who were known to have HIV
HIV Serosorting

Ecologic study in San Francisco, anecdotal reports of men who had sex with men of the same serostatus

Rates of HIV remained stable

Rates of unprotected intercourse increasing

Rates of those with unknown contacts or seeking HIV testing (due to possible contacts) decreasing

Gonorrhea / Syphilis rates exploded

Are people serosorting based on HIV status using the internet?

Not just MSM in USA

Data from Singapore, heterosexual men

Men who had sexual partners online (n=304) vs. those who had sexual partners via brothels (n=297)

Higher rates of STD's, lower rates of condom use (particularly with oral sex)

Hamilton Data

The current situation

Online solicitation for sex is becoming much easier with location based apps such as Tinder and Grindr

People who weren't considered as high risk (middle aged adults) now meeting and engaging in sex online

Injection drug use with sex (chremsex) has created a new outbreak of Hepatitis C linked to social media

What can we do?

Positive messaging at point of entry about protection and testing

Awareness of the risks associated with sexual partners acquired online

Brazil government recently created fake Tinder accounts to educate people interested in online sex during carnival

Use these apps as modes for research

Already used as HIV prevention studies

Should we be labelling similar to cigarettes?
Summary: Case 1

Social media and sexual partners acquired online have been partly responsible for an resurgence of STI's

As apps become more accessible and sexual practices change, rates may increase, and include non-STI diseases

Positive messaging, testing, and involvement of public health services with these apps is the key

Possibility of research into STI prevention

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Case 2: Social Media in the Control of Infectious Diseases

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The rationale

The internet is a wealth of communication

Infectious disease outbreaks start as a single case then spread

Typically this is reflected as an anecdotal case

How to disseminate this information effectively?

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Promed

Established in 1994 - 40 subscribers

Linked thousands of medical/veterinary/agricultural professionals over the world

Simple email listserv

Signalled the beginnings of infectious disease epidemics


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Global Public Health Intelligence Network

Public Health Agency of Canada initiative

Instead of asking subscribers to generate content, network monitors news feeds with specific search queries

First described an unusual respiratory illness in China in November 2002 - first description of SARS fed to the World Health Organization

Both ProMed and GPHIN credited with alerting Toronto and coordinating early outbreak response

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This morning I received this e-mail and then searched your archives and found nothing that pertained to it. Does anyone know anything about this problem?

"Have you heard of an epidemic in Guangzhou? An acquaintance of mine from a teacher's chat room lives there and reports that the hospitals there have been closed and people are dying."

Stephen O. Curran, M.D., on ProMED-mail, 10 February 2003
Another new virus

A novel coronavirus was isolated from a patient with pneumonia by Dr. Abu-Madani Zaid at the Virology Laboratory at Dr. Faisal Hospital, Jeddah, Saudi Arabia.

The virus was isolated from samples of a male patient aged 11 years old presenting with symptoms associated with acute respiratory disease. The virus grows readily on Vero cells and L929 cells producing CPEs in the form of rounding and syncytia formation.

The clinical picture was initially tested for influenza virus A and influenza B, paramyxovirus virus, respiratory and adenovirus, with negative results. Testing with respiratory virus ARD viral RNA led to a virus of a molecular weight appropriate for coronavirus. The virus RNA was tested also in the Dr. Faisal Laboratory in the King Abdulaziz University and was found to be confirmed. Further analysis is being carried out in the Laboratory.

The Virology Laboratory at the Dr. Faisal Hospital will be happy to collaborate with other institutes of the virus.

Weeks later

Sequenced the coronavirus and developed serologic assay

MERS coronavirus identified, outbreak currently with 25% mortality, cases found through middle east

International cooperation lead to quick identification and management of the outbreak

Still ongoing - unclear environmental reservoir...

Lags in reporting?

Google Surveillance

Typically surveillance of influenza-like illness is a mixture between clinical and laboratory features

Google used search terms (ex. influenza complications), made a model based on previous COIC data on influenza-like illness

Validated against national and regional data

Applied prospectively — picks up influenza-like illness 1-2 weeks before typically surveillance data, r values -0.5-0.88 with laboratory data

Some faults — ex. when there is local news about influenza/medications it may falsely raise the search rate

Similar model being applied to dengue

Case 2: Summary

Social media can lead to early detection and enhanced detection of pathogens, particularly in environments with limited access to "open" internet

User based internet searches also provide a wealth of data that can compliment surveillance systems
Case 3: Infectious Diseases Advocacy

Vaccines and social media

Anti-vaccine efforts have been around since the dawn of vaccination

Medical community still managed to mass vaccinate, most of the population

Splinter cells of anti-vaxxers, lead by Jenny McCarthy and Andrew Wakefield's link to autism

The imbalance of Internet-based media created by the anti-vaccine effort may be contributing

Why social media

Can now link people with similar mindsets without geographical restrictions

Can publish content easily, and skew the balance towards anti-vaccine

Tend to view similar content and skew ratings systems

Not enough published by health care providers

Lay person content

Early adopters

Random search of web in 2001 for terms "vaccination" and "immunisation OR vaccination" into 7 search engines

Analysis of first 10 sites

43% of sites had anti-vaccine content (100% on google)

"This lovely, extremely astute baby had never produced such a blood-curdling scream as she did at the moment the shot was given ... four hours later, Leo Ann was dead"

"If its immunisation really designed for prevention or care or is it pleased for increasing diseases and dependency on treatments and medicines?"

YouTube - Vaccine study

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Twitter Study

Tracked over 300,000 tweets during H1N1 epidemic around vaccination

Looked at not only message, but connectivity/endorsement between users

Negative messages not only out outweighed positive, but were more "contagious"
Dispelling misinformation

TORONTO STAR

A wonder drug’s dark side

The response

Large scale condemnation by the medical community
Many physicians used web-blogs and twitter to document the fallacy in this argument
To convey the message to other HCW
To convey the message to the general public about the dangers of this type of publication
Back and forth messaging between the Toronto star editors and medical professionals

I’m reading doctor and science writer Ben Goldacre’s new book, “I Think You’ll Find It’s a Bit More Complicated Than That”, about the widespread misunderstanding of research and results. For a year now, I’ve been trying to teach myself about statistics and science so as to find a way through the fog.

Heather Mallick, Columnist

The end result

Significant distribution over social media
Largely positive vaccine standpoint, particularly as Toronto was dealing with a concurrent measles outbreak
Responses not only local to Toronto, but national and USA health care workers came out to point out flaws in reporting

“Good god. This is appalling, ignorant, irresponsible journalism, as you well know reporting the raw data from an open adverse event reporting system in that manner, is simply misleading, and an abuse. Where data is made openly accessible we all have a responsibility to reciprocate, and analyse / report on it competently. You have abused that trust, with a platform so large that you will inflict harm. I’m disgusted and appalled that you’d invoke my name in trying to defend yourselves. The irony is, that while you use bad data to promote fear about vaccines, you miss the real big stories about the flaws in evidence based medicine.

-Ben Goldacre, tweet in response to the star article
Summary: Case 3

Using the anti-vaccine movement as an example, we see social media being a double edged sword

Let's an unscientific movement gain ground by garnering most of the internet attention

Let's scientists express their opinions freely to make changes into reporting in the media

Rules of Engagement - CPSO

1. Assume that all content on the Internet is public and accessible to all.
2. Exercise caution when posting information online that relates to an actual patient, in order to ensure compliance with legal and professional obligations to maintain privacy and confidentiality. Be aware that an identified patient may still be identified through a range of other information, such as a description of their clinical condition, or area of residence.
3. Refrain from providing clinical advice to specific patients through social media. It is acceptable, however, to use social media to disseminate generic medical or health information for educational or information sharing purposes.
4. Protect their own reputation, the reputation of the profession, and the public trust by not posting content that could be viewed as unprofessional.

Rules of Engagement - CPSO

6. Be mindful of their Internet presence, and be proactive in removing content posted by themselves or others which may be viewed as unprofessional.
7. Refrain from establishing personal connections with patients who may be remotely or physically associated with them online, as this may not allow physicians to maintain appropriate professional boundaries and may compromise professional secrecy. It is acceptable to create an online connection with patients for professional purposes only.
8. Refrain from soliciting or posting information that may be available online without prior consent.
9. Read, understand, and apply the evident privacy settings necessary to maintain control over access to their personal information, and social media protocols undertaken for personal purposes only.
10. Remember that social media platforms are constantly evolving, and be proactive in considering how professional expectations apply to any given set of circumstances.

Questions?