Social Media and Health Care: Where’s the Evidence?

**Three Messages**

* Social media is here and now—and has become the new starting point on the web.

* If Healthcare + social = Social Health (Today), THEN social health (today) = Health (future)

* Health care will continue to move forward...the only question is will nursing?
DEFINITION OF SOCIAL MEDIA

Kaplan and Heanlein, “Social media is a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of user generated content.”


DEFINITION OF SOCIAL MEDIA

Social media as “an on-line environment established for the purpose of mass collaboration.”

ZDNET PREDICTS...

- One Billion global users of social media by end of 2011
- Facebook estimates current users at 800 M
- Twitter has 100 M users as of September 2011


GLOBAL SOCIAL NETWORKING

African Social Networks thrive in a mobile culture.
Technology Review
(April 20, 2012)
SOCIAL MEDIA IMPACT

× http://youtu.be/3SuNx0UrnEo

RISE OF THE E-PATIENT

× http://youtu.be/B7ZrWSmQxcU
SOCIAL MEDIA STORIES

E-Patient Dave

* http://www.ted.com/talks/dave_debronkart_meet_e_patient_dave.html

PATIENT STORIES

Visualize This: An e-Patient’s Medical Life History: Katie McCurdy’s medical history

http://e-patients.net/archives/2012/03/visualize-this-an-e-patients-medical-life-history.html
The survey finds that, of the 74% of adults who use the internet:

- 80% of internet users have looked online for information about any of 15 health topics such as a specific disease or treatment. This translates to 59% of all adults.
- 34% of internet users, or 25% of adults, have read someone else’s commentary or experience about health or medical issues on an online news group, website, or blog.
SOCIAL LIFE OF HEALTH INFORMATION 2011

Of adults who use the internet:

- 27% of internet users, or 20% of adults, have tracked their weight, diet, exercise routine or some other health indicators or symptoms online.
- 62% of adult Internet users are on social networks, that mean 46% of all adults)

SOCIAL LIFE OF HEALTH INFORMATION 2011

“The social life of health information is robust. The online conversation about health is being driven forward by two forces:

1) the availability of social tools and
2) the motivation, especially among people living with chronic conditions, to connect with each other.
PEW INTERNET & AMERICAN LIFE

Social Media and Mobile Internet Use among teens and young adults.

Amanda Lenhart, Kristen Purcell, Aaron Smith and Kathryn Zickuhr (February 3, 2010)


PEW INTERNET & AMERICAN FAMILY

“Peer-to-peer healthcare is a way for people to do what they have always done – lend a hand, lend an ear, lend advice – but at internet speed and at internet scale.”

PEER-TO-PEER HEALTHCARE

“...It is the evolution of internet use that the Pew Internet Project has been tracking in other industries, and it is just finally having an impact on health care.”


FOUND IN CACHE

http://ebennett.org/june-2011-list-update/
CDC DASHBOARD

CDC eHealth Metrics Dashboard

Annual Summary (2010)

- 553,355,542 page views to CDC.gov overall
- 16,334,731 page views to the CDC homepage
- 69.6% of visitors spent 0-5 minutes on CDC.gov overall
- More

Most Popular Topic Pages on CDC.gov:
1. CDC Home Page, Search, A-Z
2. BMI Calculators
3. Food Safety
4. Salmonella
5. Traveler’s Health
- More

CDC DASHBOARD

CDC Facebook Friends
(2009 - 2010)
### SOCIAL MEDIA RESEARCH

<table>
<thead>
<tr>
<th>Content</th>
<th>Usage</th>
<th>Research Facilitation</th>
</tr>
</thead>
</table>
| • Media sites  
• Twitter   | • Generic  
• Targeted patient populations | • Recruitment  
• Efficacy of treatments |

### CONTENT

- Stems from question related to the quality of information being shared
- Content Analysis Techniques
- Text Mining Techniques
- General social media sites
- Analysis of specific targeted patient populations
ORIZIO, ET AL. (2010) 41 NETWORKS

- 56.1% focused on multiple health conditions
- Specific Populations: diabetes, breast/cancer, mental health
- Most were .com extensions
- 33% had quality certificates
- Most allowed patients to share & offer advice
**SPECIFIC CONTENT**

- Sajadi & Goldman (2011) incontinence on Facebook, Twitter & YouTube
  + 47% Facebook posting not useful; 60% tweets focused on information; and 47% videos developed by health care professional organizations
  + Mostly North American males, sharing experiences and limited advice

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**WEITZMAN, ET AL. (2011)**

- Alignment science & guidelines
- Safety practices
- Privacy policies & practices
- Sharing Data practices
**GREENE, ET AL (2010) DIABETES**

- 66% sharing experiences
- 29% support & community building
- Pt-centered management
- Advertisement

**KIM ET AL. (2011): YAHOO H1N1**

- General Health
- Prevention
- Questions

- Specific Questions: Symptoms & treatments
- Social Support & coping
KEELAN, ET AL. (2010) HPV VACCINE DEBATE

- MySpace—analysis (positive or negative) and their supporting arguments
- 71% women and 24% identified as parent
- More men were negative and had more friends than those who were positive
- Females who were positive had larger networks
- 52% positive; 43% negative, 6% ambivalent

TWITTER STUDIES

Scanfeld, et al. (2010) random tweets related to use of antibiotics
- Misuse & misunderstanding associated with colds and flu

Chew & Eysenbach (2010) H1N1 Tweets
- Transition from swine to H1NI, small % of misinformation
**Twitter Studies**

McNeil, et al. (2011 Seizures)
- Stigma of seizures were evident, opportunities to disseminate more accurate info

Kendall, et al. (2011) Health Promotion: Fitness
- 74% references content from outside & others
- Elliptical & Pilates were not advertisement comments whereas there were more advertisements for weight lifting.
- Promise towards support for fitness

**Summary: Content**

- Variability across social networks re: usefulness, validity & factual to personal.
- Facebook was the most popular
- Greene, et al (2010) “clinically inaccurate recommendations were infrequent, but were usually associated with promotion of a specific product or service”
- Ahmed, et al (2010) rich info being shared... peer-to-peer interaction was key aspect
SUMMARY: CONTENT

Despite risks, insights public discourse

Dissemination of public health messages

Conduct infodemiology studies

USAGE OF SOCIAL MEDIA

- Specific uses of social media by various types of networks or patient populations
- One systematic review
- Mostly descriptive studies
FROST & MASSAGLI (2008)

- Examined how patients references from personal health profiles in their patient-to-patient communication.
- Grounded Theory approach
- Comments focused on treatments more than symptoms or outcomes
- 50% included questions: about shared experiences, advice or recommendations

BENEFITS OF SOCIAL MEDIA

URL: http://www.jmir.org/2010/2/e19/
**BENEFITS OF SOCIAL MEDIA**

<table>
<thead>
<tr>
<th>Learning about their symptoms - 72%</th>
<th>Understanding side effects - 57%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helped them find someone like them - 42%</td>
<td>Helping with medication decisions - 37%</td>
</tr>
</tbody>
</table>

More Informed decision making

**WICKS, ET AL. (2012)**

Benefits sharing data Epilepsy

- 30% did not know anyone
  - Top benefit
- 47% improved QOL & sense of control
- Finding some symptoms
- Understanding more on seizures
- Learning about symptoms & treatments

Benefits & Harms Depressive SN-90% mood disorders

| 50% positive network | Peer support | Downward depressive spiral = friends & negative SNS |

Tsaousides, et al. (2011)

Facebook
- 60% use
- Family and friends

Facebook
- 40% non use
- Security password memory

Facebook
- 70% wants to learn more
- Effective Use
MCLAUGHLIN ET AL. (2012)

Social capital
- Family Interactions
- Depression

Social support
- Self Efficacy
- QOL

MCLAUGHLIN AT AL. (2012)

× 14 healthy childhood cancer survivors
× Six hypotheses, only two significant
  + Bridging social capital bonds + correlated with social network participation and video sharing
  + Decreased social support correlated with increased social network participation and shared more video narratives
BENEFITS OF NARRATIVES


EVIDENCE

<table>
<thead>
<tr>
<th>Benefit from Internet Narratives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raise public awareness</td>
</tr>
<tr>
<td>Provide info &amp; Support</td>
</tr>
<tr>
<td>Change behavior</td>
</tr>
</tbody>
</table>
SEEKING SUPPORT

• Bender JL, Jimenez-Marroquin MC, Jadad AR
  Seeking Support on Facebook: A Content Analysis of Breast Cancer Groups
  *J Med Internet Res* 2011;13(1):e16
  URL: http://www.jmir.org/2011/1/e16/

EVIDENCE

620 Breast Cancer Groups: 1,090,397 members

- Fund Raising, Awareness & Promotion
- Patient/ Caregiver Support
- Fund Raising (44.7%)
- Awareness (38.1%)
- 47% established by High school/ college students
GOLD, ET AL. (2011) SEXUAL HEALTH PROMOTION

- Systematic Review
- 178 health promotion activities included
  - 58% one Social network & 42% more than one SN
- Three networks: Facebook (71%), MySpace (46%) and Twitter (30%).
- Half from non-profit organizations
- Targeted young adults; 57% general sexual health and 25% HIV.

GOLD, ET AL. (2011)

- Facebook and Twitter the most active
- Future research needs to evaluate the process and outcome variables associated with social networks and their impact on behaviors.
SUMMARY: SOCIAL MEDIA USAGE

- Perceived benefits and some potential harm
- Potential to facilitate data centered patient conversations
- Need for more studies including comparative effectiveness studies

SOCIAL MEDIA FOR RESEARCH PURPOSES

- Allison (2009) how to leverage social network for clinical trial recruitment
  + PatientsLikeMe
  + Inspire
  + 23andMe
  + Susan Love’s Army of Women
  + Diabetic Connect
  + Trial X
FENNER, ET AL. (2012)

Exploratory Study Facebook 16-25 year old female Good for non urban recruitment

BENEFITS OF SOCIAL MEDIA


Amitriptyline & modafinil
BENEFITS OF SOCIAL MEDIA

- The study of patient reported treatment histories provides:
  - Real time account of their utilization and responses
  - Identification of new research variables to be systematically studied

PATIENTS LIKE ME STUDIES

PATIENT’S NETWORK PREDICTS OUTCOME

- Conducted a study of their patients and their observations.
- 12 months before and after
- Methodological criticisms
- Rich source data

WEITZMAN, ET AL. (2011)

- Online diabetes community to share data for public health research
- TuDiabetes Network & TuAnalyze
- “81.4% choose to include their data in charts, graphs and maps....with 34% sharing personal A1c data on their profile page”
- Efficient method for data sharing and bidirectional communication
SUMMARY OF THE EVIDENCE

- Infancy stage
- Descriptive, focus on evaluation of content & uses by patient populations
- Effective dissemination of info to public
- Growing body of evidence of emotional support especially for cancer & chronic diseases such as diabetes

SUMMARY OF THE EVIDENCE

- Various data and text mining techniques
- Recruitment of research subjects
- Rich self-reported patient data resource

- Serve as a foundation for the development of social media ...but need a research agenda examine the effectiveness and impact on outcomes
RESEARCH DIRECTIONS

Kibbe & Kvedar (2011) stated...
“this is a field in its infancy that, by definition, and according to the values that drive it... should be developed as a collaborative effort of all stakeholders”

WISDOM OF THE CROWDS

Connect, Share & Collaborate
Perhaps WIN collectively can chart the course of a social media research agenda
PARTING THOUGHTS

If Healthcare + Social = Social Health (Today),

THEN social health (today) = Health (future)


PARTING THOUGHTS

How ideas spread….how does something become viral…. Emotional Resonance is the key....

“ Social has become the new starting point...”now how people get their content

Impact on how you organize your content...what happens if an industry becomes social?

Jonah Peretti, CEO Buzzfeed on Charlie Rose http://www.charlieroose.com/view/interview/12308
Sharing Human Interaction

Emotion

PARTING THOUGHTS: PERETTI (2012)

THE CHALLENGE

- It is clear from both the statistics and the current uses that there is no returning to a pre-social media healthcare, and that health care will continue to move forward and incorporate more uses of social media.....

-The only question is WILL YOU?

WILL YOU?

✗ As an Educator, will you explore how to best way to incorporate social media experiences for your students?

✗ As an Educator, will you become a mentor to help students learn how to effectively use social media?

WILL YOU?

✗ As a Researcher, will you be the one who develops & tests the new theory of social health in nursing?

✗ As a new Researcher, will your research trajectory focus on the impact of social health on patient outcomes, health status and well being?
WILL YOU?

- As a Clinician, will you explore the potential of social health with your colleagues?
- As a Clinician, will you explore how you can engage and enhance team-based care?
- As a Clinician, will you explore how you can engage your patient and their families in social health practices?

WILL YOU?

- As an Administrator, will you help to eliminate unnecessary barriers for the exploration of social health?
- As an Administrator, will you create and support an culture of innovation that will support the development and research of social health?
THREE MESSAGES

✗ Social media is here and now—ubiquitous and has become the new starting point on the web

✗ If Healthcare + social = Social Health (Today), THEN social health (today) = Health (future)

✗ Health care will continue to move forward, the only question is will nursing?

E-PATIENT RAP

✗ Give me my damn data
✗ ® . Rap song by e-patient dave
✗ .® . http://youtu.be/0b4li7N_7Ck
THANK YOU

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