Health Communication
At the Nexus of Social Media & Popular Culture

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Outline

1. Motivation: Unmet Medical Needs
2. Social Media & Participatory Medicine
3. History & Cultural Functions of Celebrity
4. Teachable Moments & How They Work
5. Theory & Design Strategies for Health Behavior Change
6. The Goody-Gaga Effect
7. Call to Action

Twitter hashtag
#goodygaga
The mission and mantra of the pharmaceutical industry is to address “unmet medical needs,” a noble calling that represents the best and highest aspirations of drug developers.

Despite decades of time and many billions of $$ of investments in basic and applied research, tech development and changes in management and organizational structures, it still takes 10-15 years and $500 million to $2 billion to develop a new drug.
A Different Perspective

- What about the needs of consumers for better access to existing medical knowledge and practices?
- Could increasing health awareness and medical knowledge lead to better use of existing resources including prevention and screening methods?
Online Health Information Retrieval by Consumers and the Challenge of Personal Genomics

Mark S. Boguski

INTRODUCTION

In an age of personalized medicine, nothing represents the zeitgeist more than individual consumers using the Internet and World Wide Web to seek medical and health information. According to surveys by the Jupiter organization and Harris Interactive, 71% of people who use the Internet also used it to seek health information in 2007, and this percentage, which represents an estimated 160 million people in the United States, had increased by 37% since 2005 (Anonymous, 2007b; Levy, 2007).

Consumers perform health information search (HIS) and retrieval (HIR) for themselves as well as for friends and family. Studies have shown that most of these consumers do not later discuss the information with a health-care provider and that, for many people, the Internet may be the primary or even sole source of health information. (Fox and Fellows, 2003). Seventy percent of people who obtain health information online say that it has influenced a decision about their treatment.

Clearly, it is important for health care professionals to understand how their patients find health information and the pitfalls associated with this activity. Indeed, given the challenges that consumers face in obtaining quality health care information from Internet sources, health-care providers will increasingly be in a position where they have to act as reviewers of information and as educators of patients who bring this information to their attention.

CHARACTERISTICS OF CONSUMER SEARCHES FOR HEALTH INFORMATION

A 2007 study by the Pew Internet & American Life Project (Fox, 2006) showed that the top 10 reasons American adults search online for health information are:

- a specific disease or medical condition;
- a particular medical treatment or procedure;
- diet, nutrition and supplements;
- exercise or fitness;
- prescription and non-prescription drugs;
- a particular doctor or hospital;
- alternative medicine or treatments;
- health insurance;
- mental health issues;
- environmental health hazards.

Zeng and Tse (Zeng and Tse, 2006) reported that, in performing searches, consumers use query terms that consist of...
Social Media

- Media for social interaction using highly-accessible & scalable publishing techniques
- Web 2.0-based technologies to turn communication into interactive dialogue
- Ideologies & technologies allow the creation & exchange of user-generated content
- Blends technology & social interaction for the co-creation of value

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Participatory Medicine

- A cooperative model of health care in which
  - networked patients shift from being mere passengers to responsible drivers of their health
  - providers encourage and value them as partners
- Based on the concept of the “e-patient”
  - “e” is variously defined as empowered, engaged, equipped, enabled, etc.
  - manifesto of the movement, “e-patients: how they can help us heal healthcare,” published by the late Dr. Tom Ferguson in 2007
  - the most famous e-patient today is Dave de Bronkhart
What about the rest of us?

If You're Reading This, You May Be a "Slack-jawed Yokel"

By: Michele R. Berman, MD | December 03, 2010

Dan Olds from Beaverton, Oregon characterized those of us who are interested in popular culture as "slack-jawed yokels" in a recent interview with Sharon Gaudin in Computenworld.

Olds’ characterization was based on the fact that, in 2010, seven of the top 10 searches on Yahoo! were about celebrities:

1. BP Oil Spill
2. World Cup
3. Miley Cyrus
4. Kim Kardashian
5. Lady Gaga
6. IPhone
7. Megan Fox
8. Justin Bieber
9. American Idol
10. Britney Spears

Mr. Olds concluded that the Internet is not a serious tool for information dissemination because this Yahoo! Top 10 list did not include searches about the global economic crisis, the earthquake in Haiti, or the mid-term elections in the U.S.

Could it be that us yokels simply get our "hard news" by going directly to sites that specialize in this information (e.g. CNN, The New York Times, Wall Street Journal, The Economist, etc.) rather than using search engines to find it?
The modern concept of celebrity was formed circa 1895-1920, associated with the work of newspaper columnist Walter Winchell.

Over the next century, “celebrity” achieved cultural pervasiveness, enabled by waves of communication technologies: radio, movies, television, the internet.

Early critiques expressed an elitist distaste for the phenomenon:

- Daniel Boorstein: “The celebrity is a person well-known for their well-knownness.”

Later scholars, such as Prof. Graeme Turner, have pursued more disinterested and less judgemental approaches.
Celebrity: Cultural Functions

- Prof. Graeme Turner, Univ. of Queensland Centre for Critical & Cultural Studies: “Celebrity may play positive roles or productive social functions in society”
  - In the formation of cultural identity
  - As a mode of discourse that results in pleasurable social exchange
  - In the construction of community

- Hamish Pringle, Institute of Practitioners of Advertising:
  - “The role that celebrities play in people’s lives goes beyond a voyeuristic form of entertainment…
  - ..but actually fulfills an extremely important research & development function for them as individuals and for society at large.
  - People use celebrities as role models and guides.”
Teachable Moments

Robert Havighurst (1952) *Human Development and Education*

"A developmental task is a task which is learned at a specific point and which makes achievement of succeeding tasks possible. When the timing is right, the ability to learn a particular task will be possible. This is referred to as a 'teachable moment.' … unless the time is right, learning will not occur.


“The findings suggest that the teachable moment is not necessarily unpredictable or simply a convergence of situational factors that prompt behavior change but suggest the possible creation of a teachable moment through clinician-patient interaction.”
Published work implies that cueing events must be direct, personal life experiences such as an office visit or hospitalization, notification of abnormal test results or a disease diagnosis and implies that the social interactions must occur synchronously in real time.

We believe that teachable moments can be created using cueing events from popular culture and that cueing events can be vicarious, asynchronous interactions mediated by social networking technologies.
Teachable Moments are based on accepted conceptual models and theories of behavioral change, e.g.

- Health Belief Model
- Social Cognitive Theory

Mable Kinzie, Univ. of Virginia Curry School of Education, has developed instructional design strategies for health behavior change.

Patient Education & Counseling 56(1):3-15, 2005
### Kinzie’s 5-step Framework for Developing Instructional Materials

<table>
<thead>
<tr>
<th>Framework Step</th>
<th>Our Implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Gain attention</td>
<td>Famous people’s health conditions in the news</td>
</tr>
<tr>
<td>2. Present stimulus material</td>
<td>Information on specific conditions</td>
</tr>
<tr>
<td>3. Provide learning guidance</td>
<td>Links to more information</td>
</tr>
<tr>
<td>4. Elicit performance &amp; provide feedback</td>
<td>Surveys, blog comments, tweets/retweets</td>
</tr>
<tr>
<td>5. Enhance retention &amp; transfer</td>
<td>Different celebrities can have the same disease; repetition enhances retention. Normal social discourse transfers knowledge to others.</td>
</tr>
</tbody>
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Collect
Organize
Personalize
Share

Results of searches on health topics

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Steve Mazan was Literally Dying To Do Letterman

Tisha Campbell-Martin reveals she has Sarcoidosis.

by Dr. M on FEBRUARY 5, 2011 in ENTERTAINMENT

Actress Tisha Campbell-Martin tells People magazine that, although she does have the disease sarcoidosis, contrary to tabloid reports, she is not dying from the disease. The My Wife and Kids and Rika Rocks star said in a statement to People: “Thank you, everyone, for your concern, however, no worry is needed. I was diagnosed with [...]

Polls close Midnight Sunday February 13

VOTE FOR CELEBRITY DIAGNOSIS

For bringing you the medical facts behind the headlines

VOTE NOW!
Super Bowl's "Darth Vader" Needed His Heart Fixed

By: Michele R. Berman, MD  |  February 08, 2011

With an audience in the neighborhood of 100 million people, it’s no surprise that advertisers pull out all the stops for their Super Bowl ads, especially when it is reported that half the viewers watch the game for the commercials alone.

The most popular commercial during Sunday's contest between the Green Bay Packers and the Pittsburgh Steelers was, by many accounts, a Volkswagen commercial where a young boy tries to "channel his inner Darth Vader". The video has become a viral hit on YouTube, with over 16 million views to date.

Volkswagen Commercial: The Force

Who is the boy behind the mask? It's 6-year-old Max Page, who was a member of the cast of The Young and the Restless from 2009-2010 playing Reed Hellstrom.

Physician office call volumes increase in association with celebrity health news.

Healthcare providers Need to be able to anticipate when patients may call about a specific disease or condition.
The Goody-Gaga Effect: Jade Goody

D. Metcalfe et al.  
J Public Health (Oxf)  
2010

Media Coverage and Public Reaction to Celebrity Cancer Diagnoses

By: Michele R. Berman, MD | September 21, 2010

An article published in the Journal of Public Health last month reported aspects of increased public interest in disease prevention following celebrity diagnoses. The British research group studied the case of Reality TV personality Jade Goody (pictured) who died in March 2009 from cervical cancer. The study looked at newspaper coverage of Ms. Goody’s illness and the extent to which articles conveyed public health messages and public information-seeking behavior as a reflection of increased awareness of the disease.

Ms. Goody, 27, became a public figure as a result of her role on the U.K. reality TV show Big Brother. The media reported her diagnosis of cervical cancer on August 19, 2008. From that date until 10 weeks following her death, the authors of the study cataloged 1,203 articles about her case published in 17 national British newspapers. Analysis of these articles showed that only 9.6% provided information sufficient for readers to infer a method of reducing personal cancer risk, with the majority (85.3%) highlighting screening. Many fewer articles provided useful information on primary prevention methods including HPV (human papilloma virus) vaccination, limiting the number of sexual partners, condom use and smoking cessation.

We think Gary Schwitzer would agree that such coverage would not meet his standards for health journalism.

The authors of the study also looked at internet (Google) search behavior for specific disease information during the period in which the 1,203 articles were published. Unmistakable increases in search activity for information about cervical cancer were observed at three key time points in the course of Ms. Goody’s disease: her initial diagnosis, news of her terminal prognosis on February 14, 2008, and news of her death (see Figure 1 here).

The researchers also observed corresponding increases in the number of women undergoing cervical screening by the U.K. National Health Service.

The authors of the study concluded that:

“Health promoters should not rely on popular media sources to maximize the public health potential of celebrity illness. Instead, they should react promptly [italics mine] to future celebrity diagnoses to maximize public health opportunities through working with news organizations. As celebrity illness can precipitate increased online searching for health terms, this reaction should include making timely, effective and reliable advice available to online health information seekers.”
Lady Gaga’s family history and testing for lupus

by DR. B on MAY 26, 2010 in ARTICLES and DIAGNOSIS, ENTERTAINMENT

Recently, People Magazine reported that Lady Gaga, 24, was “tested for lupus” and told the The Times of London that her aunt, Joanne, died of this disease (12 years before Lady Gaga was born). Gaga, who real name is Stefani Joanne Angelina Germanotta, was named after her aunt Joanne and also her grandmother Angelina Germanotta. Lupus can run in families and there are new genetic tests that can tell whether or not you are at risk for this autoimmune disease.

The immune system is essential to survival, and even a small decrease in immune function can leave a person susceptible to infection. But the immune system itself can also cause disease, by inappropriately attacking the body’s own organs, tissues, or cells. More than 80 autoimmune diseases are known. Some, such as type 1 diabetes, attack specific organs, while others, such as systemic lupus erythematosus (SLE), involve multiple organs. Although many autoimmune diseases are rare, collectively they affect approximately 5 to 8 percent of the U.S. population. A disproportionate number of people with autoimmune disorders are women.

We have previously reported on lupus (short for systemic lupus erythematosus or SLE) when Lucy Vodden, who inspired the Beatles’ song “Lucy in the Sky with Diamonds,” died from this disease last year. Images of butterflies and wolves are associated with lupus because of the butterfly-shaped rash that appears on the face of people with the disease. When lupus was first discovered hundreds of years ago, doctors of that time thought that patients looked like they had been bitten by wolves (lupus is the Latin word for wolf).

When Lady Gaga said she was “tested for lupus”, this could mean one of two things.

• Blood tests that can tell whether you might have the disease now
• Gene tests that can estimate the risk for developing the disease in the future

Lady Gaga did not specify what kind of tests she had and we respect her right to privacy. Gaga did say, however, that she doesn’t “want anyone to be worried.”
**define: the Goody-Gaga Effect**

Sharply increased volume of search engine traffic for specific diseases or medical conditions that correlates with a celebrity association with that disease or condition.
Summary & Conclusions

Susannah Fox – Pew Research Internet & American Life Project
“Americans' pursuit of health takes place within a widening network of both online and offline sources. Whereas someone may have in the past called a health professional, their Mom, or a good friend, they now are also reading blogs, listening to podcasts, updating their social network profile, and posting comments. And many people, once they find health information online, talk with someone about it offline.”

Dr. Barron H. Lerner – Columbia University Mailman School of Public Health & author of When Illness Goes Public
The public increased their knowledge of medical topics and conditions, not because they were seeking health information but rather as a consequence of their primary interest in celebrities’ lives.

Dr. Katherine Smith – Johns Hopkins Bloomberg School of Public Health
Media coverage of celebrities and found little material that conveys useful health information. We conclude that “media attention to such newsworthy events is a missed opportunity that can and should be addressed.”

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Call to Action

Open invitation for expertise and funding collaborators to measure the quantitative impact of Celebrity Diagnosis on health awareness, medical knowledge and/or health behavior change.

Contact drb@celebritydiagnosis.com

Celebrity Diagnosis and Celebrity Diagnosis Professional Edition have been nominated for the annual medGagdet Weblog Award in the categories of Best Medical Blog and Best New Medical Blog

Vote for our sites and we will donate any winnings to charity

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