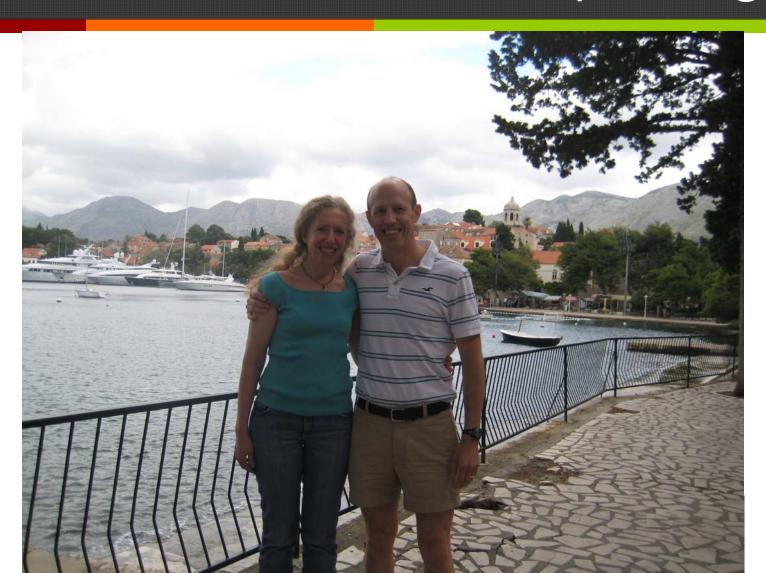
### Learning from Patient Blogs

Lisa Gualtieri, PhD, ScM
Department of Public Health and Community Medicine
Tufts University School of Medicine
lisa.gualtieri@tufts.edu
@lisagualtieri

June 24, 2013

## 4 years ago!





# Thank you for invitation



## 19 million people write blogs

### Why I Run: A Reflection at the "Action Stage"

#### Why I Started

I started running 15 weeks ago because I decided to do the opposite of what I felt like doing. I was exhausted after teaching a 1-week course and, when resting didn't help, I decided to run. I was already exercising, so, when I tried Couch25K, which my son recommended, I was beyond "couch". But my previous attempts to run had been not serious (in college), had been at too fast a pace to sustain (a few years ago), or purely in my head (New Year's resolutions). The latter seems to be common; when I told people I was running, many said, "I've been thinking of starting too." It's like when people view modern art and say, "I can do that." But most don't.

Using the language of Transtheoretical Model of Change, these people are at the precontemplation stage. I was too, until I started my "Do the Opposite" plan. The other stages are contemplation, preparation, action, and maintenance. I am solidly at the action stage.

#### What I Have Accomplished So Far

Even though I didn't follow Couch25K, it made me aware of starting slow and building up. I knew the importance of a schedule thanks to my runner husband, Mike, and the exercise class I've been going to for years. I committed to running three times a week, and have only had one time I run twice (and a few I've run four times).

While my first run was six minutes, I have now completed a 5k. My longest run was 1:04:13, which included going up Nob Hill in San Francisco. I called this "breaking.

#### Lisa Gualtieri, PhD, ScM



Lisa Gualtieri
is Assistant
Professor in
the
Department of
Public Health
and
Community

Medicine at Tufts University School of Medicine where she teaches Online Consumer Health, Social Media and Health, Mobile Health Design (online), and Digital Strategies for Health Communication (1 week summer institute). Contact Lisa: lisa.gualtieri@tufts.edu

#### @lisagualtieri

Looking forward to it! RT @DrexelU\_CCM: Life Online workshop @marylgray @ybika @annettemarkham @shumarw @BrentLuvaas bit.ly/14Wvalk 8 hours ago

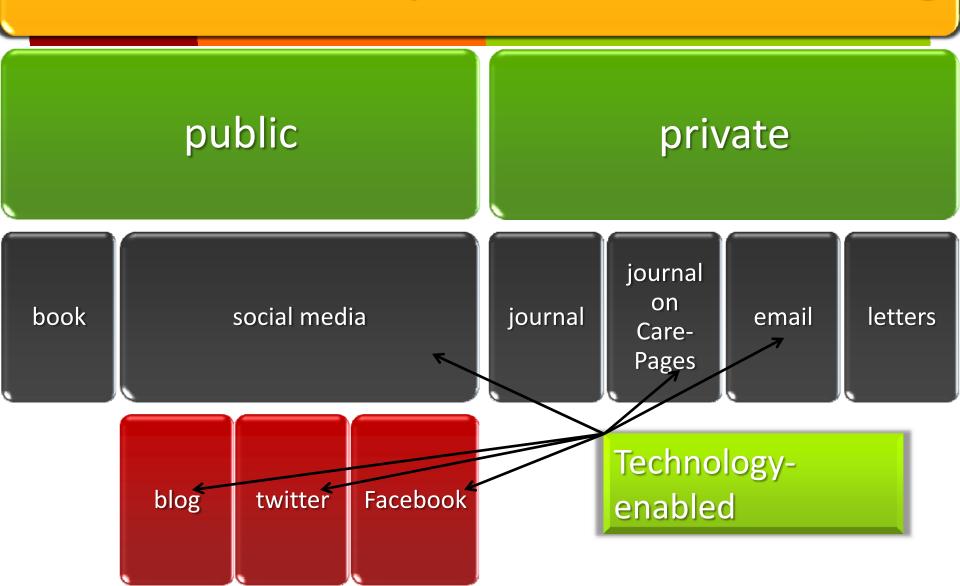
@00Blum @Saif\_Abed of use to what? 1 day ago

Thanks! RT @lynntolson Thanks 2 @abuse\_journals @lisagualtieri

# People have long communicated the experience of illness in writing

public private book journal letters

# Technology has enabled new ways to communicate the experience of illness in writing



## Blogs are different

- Online communities and social media
  - Short bursts, not continuous
- Blogs allow author to create a micro-community
  - Open format unconstrained by
    - Length
    - Categories
    - Topic
  - Dated and tagged
  - Incorporating multimedia

### Problem Statement

Lack of research on the phenomenon of patients with various chronic illness diagnoses writing blogs

## How many patient bloggers?

- 13% of US *e-patients* write a blog about their diagnosis and treatment (Pew 2010)
  - e-patients refers to the 61% of US adults who use the Internet for health information
- Of the 69% of US adults reported having Internet access, 7% reported blogging (HINTS 2007)
- Fertile field with
  - More than 133 million individuals living with chronic illness in the US
    - National Center for Health Statistics, 2006
  - The popularity of blogs and other social media
  - Increased visibility on hospital and media websites
- Assistive technologies make writing possible for individuals with disabilities and chronic illness

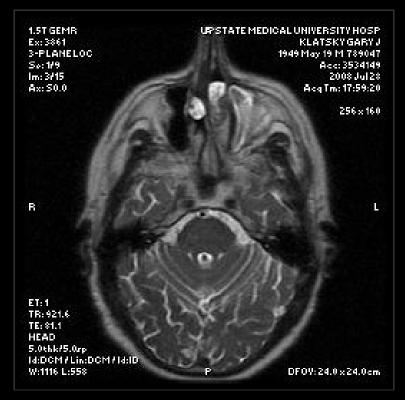
## How many blogs?

- 24,000 health or health-related blogs
- Largest number of patient blogs are about cancer
- Women with or survivors of breast cancer are particularly active

### Initial Interest

- Gary Klatsky, Professor of Psychology at SUNY Oswego, who blogged about his cancer
- His final post was January 10, 2009
- Continued for short time by family to announce funeral and scholarship fund

### new year



Thanks to all my family and friends for all the love and support you gave me last year that is shat kept me going I lo e you all. I had a scan yesterday Friday 1/9/09 There is some spreading of thecancer The good news is that the Avastine is still working, keeping the blood supply to that new growth from developing. There are also other drugs to try despite the news I still feelike the luckiest man who ever lived

### MEDICAL UPDATE

THIS IS A SORT OF STREAM OF CONSCIOUSNESS RELATED TO MY RECENT BRAIN INCIDENTS. I APOLOGIZE FOR THE LACK OF EDITING ALTHOUGH I HAVE NO MAJOR COGNITIVE IMPAIRMENTS, THERE IS STILL SOME SLIGHT MOTOR LAG WITH MY LEFT HAND RESULTING IN TOO MANY TYPOS AND MISSING LETTERS.

## Many patient bloggers

- Most, like Gary's, are written by individuals about their diagnosis and treatment
  - Not widely read
  - Not heavily commented
  - Hard to find: <a href="http://garysurgery.blogspot.com/">http://garysurgery.blogspot.com/</a>
- A few are widely read and promoted

## Leroy Sievers, NPR

**FIND A STATION** 

SEARCH

go

home

news

arts & life

music

programs •

listen 🕶

**◄**) HOURLY NEWS

PODCASTS

**MYCANCER** 

< previous post

next post >

### I Am Not My Disease

07:24 am

July 12, 2006

E-mail 🖂

Share <

Print

Comments (0)

Recommend (0)

by LEROY SIEVERS

Getting cancer turned out to be a good career move for me. That's a joke I've told a number of times, but it does have the ring of truth to it. Because of my disease, I have this blog, the podcasts, the commentaries. And I have a unique and valuable forum to talk to all of you. I wouldn't have this if I

66

The cancer has changed just about everything. My life, my career, my body. But aside from that, I am still, at the core, the same person I was before. Maybe a little wiser, but the same person.

99

Support for NPR is provided by:



Become an NPR Sponsor

### search my cancer

Search

search

### about 'my cancer'

After that day, your life is never the same. "That day" is the day the doctor tells you, "You have cancer." Every one of us knows someone who's had to face that news. It's scary, it's sad. But it's still life, and it's a life worth living. "My Cancer" is a daily account of my life and my fight with cancer.

### INSIDE HEALTH

### NUTRITION



Recipes for Health

### HEALTH<sub>®</sub>



Patient Voices: Migraine

### CANCER JOURNAL



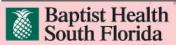
One Man's Story of Living With Prostate Cancer

### From 1 to 25 of 699 Comments

1 2 3 ... 28 Next »

. March 31, 2009 I just lost my 13-year-old Toby this past week. Thank

## Mimi Rodriguez, Baptist Health South Florida



**Healing Journeys** A Blog About Breast Cancer



#### 2 comments to My Thoughts on Cosmetic Surgery

Mimi Ramirez

February 8th, 2010 at 7:20 pm · Reply

How proud I am that you are my daughter. Writing about your journey with "BC" from the day you were first diagnosed, is helping many women reading your blog understand that this decease that affects so many of us, is curable by early detection. I urge your readers to do their own monthly screening, and to schedule a mammography if they notice anything unusual. Most cases turn out to be nothing serious, but, if they have to face your situation, they should gather as much information as you did, ask the doctors as many questions as you did, pray to God as you did, and also as you did... ask your family and friends for their prayers and their support. God will be there to help those seeking Him, and His intervention I am sure, is the reason why you are doing so well. Our prayers were answered, and your life as well as mine, have been enriched and blessed by this experience. You are blooming and looking more beautiful thank ever. Tribulations abound, but life is beautiful and faith can move mountains. Let us all enjoy life to the fullest one day at a time, and receive each brand new day with a smile of gratitude, positive attitude, renewed faith in God and joy for life . When this last chapter of your journey is completed and you stand in front of a mirror, you will not see your scars as those will vanish eventually, you will see yourself totally cured of "BC" and .... with two new perky and beautiful breasts and a cleavage you didn't have before. With all my love, my prayers and my blessings to you and all your readers. Mami.

[Reply]



February 16th, 2010 at 4:00 pm · Reply

Mom, I love you and I could not do this without you. I am the one who is proud to have a mother like you. I am truly blessed.

[Reply]

#### Leave a Reply

Name (required)

Mail (will not be published) (required)

Website

You can use these HTML tags

Security Code:





En Español

#### **About Me**



Mimi Rodriguez is a 44 year-old homemaker, married for 21 years and her daughter is 10 years old. Mimi

Print This Post

### Moving On

I'm sorry to say that I've decided not to continue writing this blog.

I'm having some issues that I need to address and I just don't want to write any more.

I find myself less and less at the computer these days. I have a pile of unread emails. Also, my daughter has been sick with her fifth bronchial infection this year and since it's her last year in elementary school, I've been busy trying to get her into a good middle school. I'm trying very hard to return to my normal, everyday life and writing a blog is not something I would normally do. However, I am glad that I shared my story and hope that the women who read it were inspired or comforted.

All of my life I've been a worrier and now I find that I'm worrying about a cancer recurrence. I think what I need right now is to get into a good support group and to reconnect with the breast cancer mentor that I was assigned through the program, A Buddy for You . I'm sure that I'm not the only cancer survivor to be worried about a recurrence. I'm also hoping to find some

#### Recent Posts

Moving On

Problems with My Nipple

Reconstruction

My Breast Reconstruction Surgery

Shopping for New Breasts Part II Breast Cancer License Plates

#### Categories

Healing Journeys

National Breast Cancer Awareness

Archivee



### MY NEW YORK MINUTE

One guy's perspective on navigating through prostate cancer diagnosis and treatment



ABOUT PROSTATE CANCER

ABOUT PCF

CONTACT DAN

SUBSCRIBE BY EMAIL

SUBSCRIBE TO RSS

### 7 Weeks and One Day... That's My IMRT Plan





Yesterday afternoon I began my radiation therapy. Let the radiation flow. A total of thirty-six Intensity Modulated Radiation Therapy (IMRT) sessions is prescribed by my personalized treatment plan. The number was arrived at by my radiation oncologist, a radiation physicist and a dosimetrist. After reviewing my three-dimensional planning CT taken last week, they calculated a complicated equation based on [...]



coping, side effects, treatment

### Advancing and Reaching the Disproportionately Affected





African-American men are 60 percent more likely to be diagnosed and 2.4 times more likely to die from prostate cancer. With the stark reality that black men and their families are more more likely to be affected by prostate cancer than any other group of our population, two events provided a fitting end to last week's Advance [...]

#### About this Blog

This is a blog by Dan Zenka, Vice President of Communications for the Prostate Cancer Foundation (PCF) and newly diagnosed prostate

cancer patient.

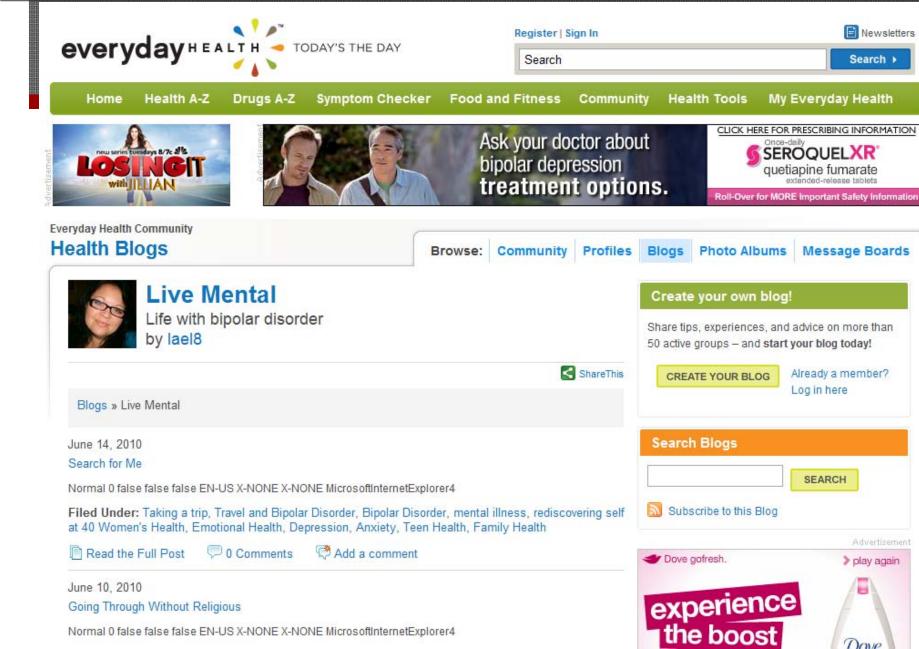


View the first post here

#### Survivors & Supporters Breakfast



### Some site support public or private blogs



## Examples are Everyplace...



RT @theBetesNow: 24/7 Balance

http://dlvr.it/5nS6N #dblog #diabetes

Reply Retweet

RT @tudiabetes: "Malnutrition Diabetes": this Diabetes that strikes those w/ poor Nutrition. Dr Meredith Hawk... http://bit.ly/blfUFs #dblog

15 minutes ago via TweetDeck

RT @Diabetic\_lz\_Me: RT @SugabeticDotCom: Not A Coincidence, A Reminder. http://bit.ly/dv5wYk #dblog

18 minutes ago via TweetDeck

RT @diabetesblogs: Last Chance http://dd4.us/dmT49l #diabetes #dblog

about 1 hour ago via TweetDeck

RT @DiabetesNews EASD: Early Diabetes Not Helped by Intense Therapy - MedPage Today http://is.gd/foZba

about 1 hour ago via web

RT @txtngmypancreas: Worst possible day 4 an insulin pump 2 fail. New #dblog http://bit.lv/9KJlr1

Home Profile Find People Settings Help Sign out Name The Poor Diahe Location Cleveland Web http://thepoordia... Bio A type 2 diabetic blogger, self management technician 2,136 following followers listed Tweets 2.016 Favorites Lists @thepoordiabetic/diabeticsavings View all Actions message thepoordiabetic block thepoordiabetic report for spam You both follow View all. Following



## Preliminary study

- Survey to people we knew and posted on Twitter
- From 24 respondents we learned most start and maintain a blog to
  - Help others with the same diagnosis
  - Communicate with family and friends
  - Express feelings
  - Track the progression of the disease and treatment
- Quotes
  - "As the months have passed, I have been making my posts philosophical as well as informational; expressing my thoughts as well as my condition. I find some comfort in doing that."

# Analysis of preliminary study indicated benefits

- Individual patients and caregivers
- Family and friends of patients
- Other people in similar situations
- Healthcare providers
- Medical community

## Hypothesis

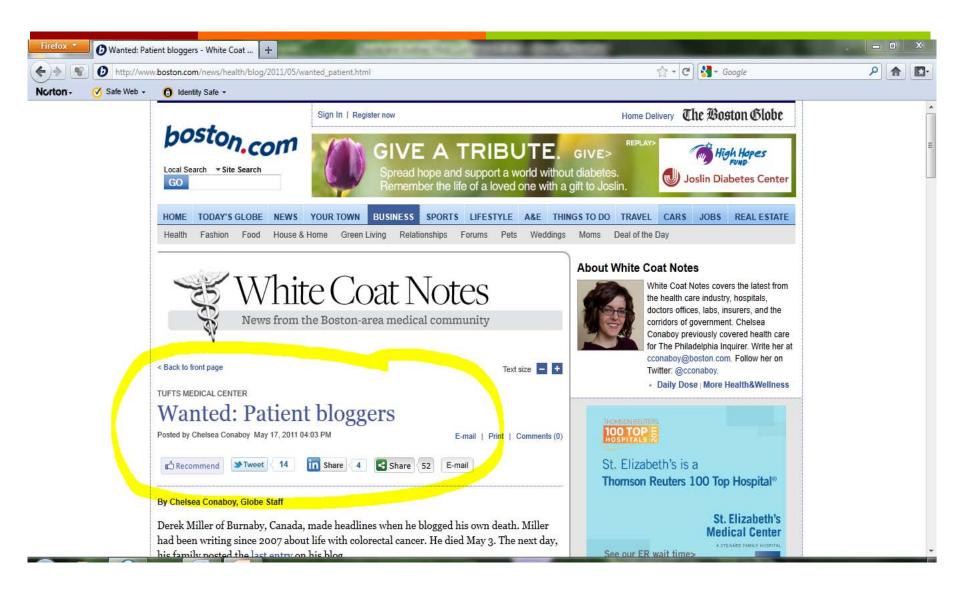
Communicating the experience of illness through blogging provides positive psychosocial benefits to some patients with chronic illness.

### Theoretical framework

- Research is grounded in nursing theory
- Dr. Margaret Newman's theory Health as Expanding Consciousness recognizes that health is an awareness or consciousness of the evolving interaction between the individual and his or her environment and is possible regardless of presence or absence of disease.

## Project methods

- Literature search revealed a paucity of information on patient blogs
- Initiated formative qualitative research to design an online survey
- Developed an online consent to fully inform participants and meet Tufts Medical Center IRB regulations
- IRB submitted and approved by Tufts Medical Center
- A convenience sample of **41 current patient bloggers** solicited through social media forums, online patient communities, and Boston Globe
- Data analyzed for psychosocial themes as well as demographic data
- Recognize that the cohort is a self-selected group of English speaking patient bloggers



## Survey instrument

- 34 question online survey tool designed and tested through Survey Monkey™, a widely used survey aggregator/collector allowing for safe, SSL encrypted data transmission
- Survey questions consisted of a mix of closed-ended multiple choice and matrix design questions and open-ended essay/comment questions inquiring on motivational and psychosocial factors relating to blogging.
- Demographic data questions (age range, gender, educational level, race/ethnicity) are also asked
- Any question in the survey could be skipped by the respondent with the exception of Question 1 which served as the informed consent and was required to be answered in the affirmative

## Sample questions

- What is the diagnosis or illness that prompted you to begin a blog?
- Has writing a blog made a difference in how you have dealt with your illness? How?
- Has writing or reading patient blogs changed your sense of connection with others?
- Have you shared your blog with your health care provider?

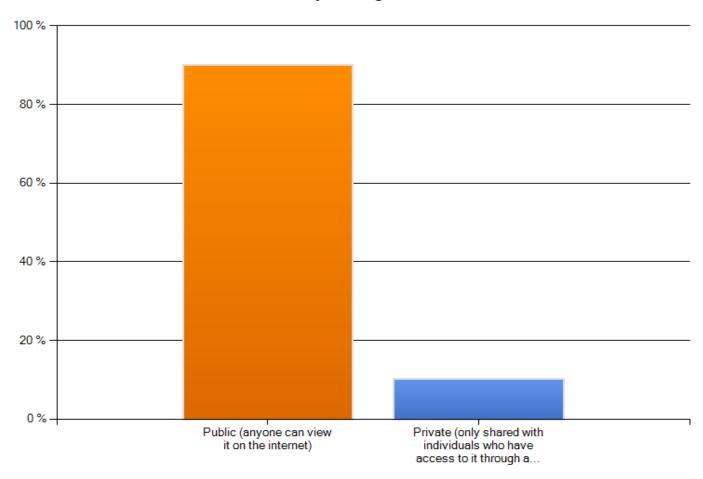
### Results

- → High level of co-morbidities among the sample group:
  - Isolating illness, such as chronic pain, fibromyalgia, depression
  - Rare diseases or uncategorized illness
  - Cancer, particularly breast and ovarian
  - Diabetes
  - Common features included chronicity of illness and potential for pain and suffering
- Demographic data revealed:
  - Relatively homogenous cohort
  - Predominantly female
  - Caucasian
  - Highly educated
  - 79% between ages of 25-55

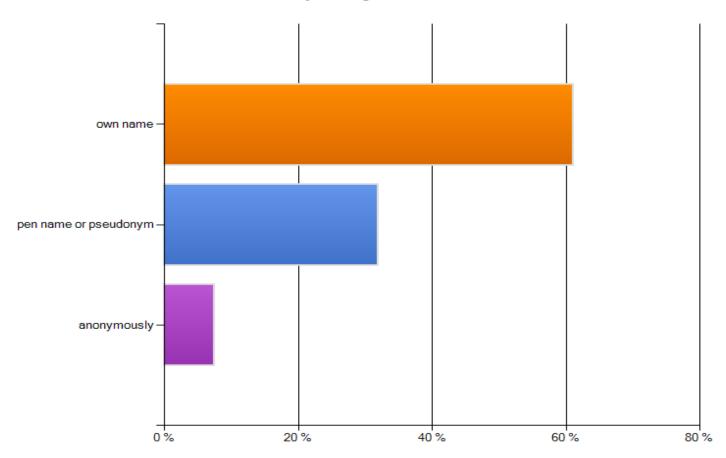
## Public nature of blogs

- Majority of blogs were searchable and public
- Most bloggers used their own names when blogging versus a pen name or blogging anonymously
- >80% shared their blogs with friends and family members
- >95% read other people's health/illness blogs
- >80% have contributed comments on other people's blogs
- Majority of respondents engaged in other forms social media, in addition to blogging (most common were Facebook, Twitter)

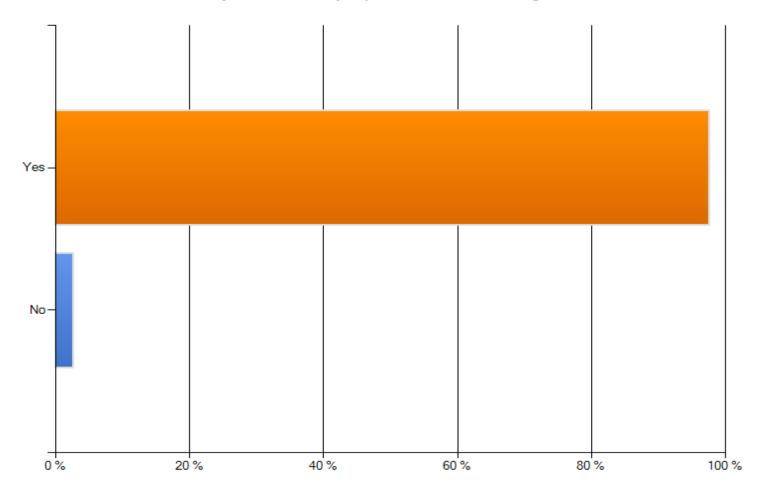
### Is your blog:



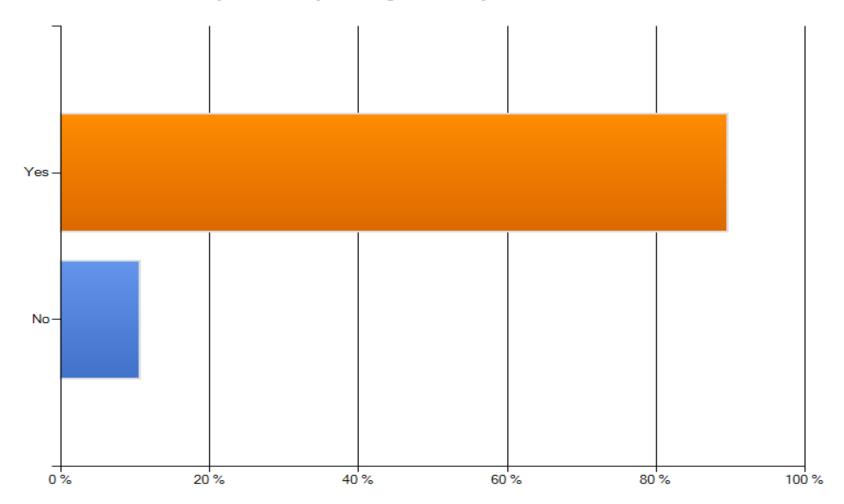
### Do you blog under:



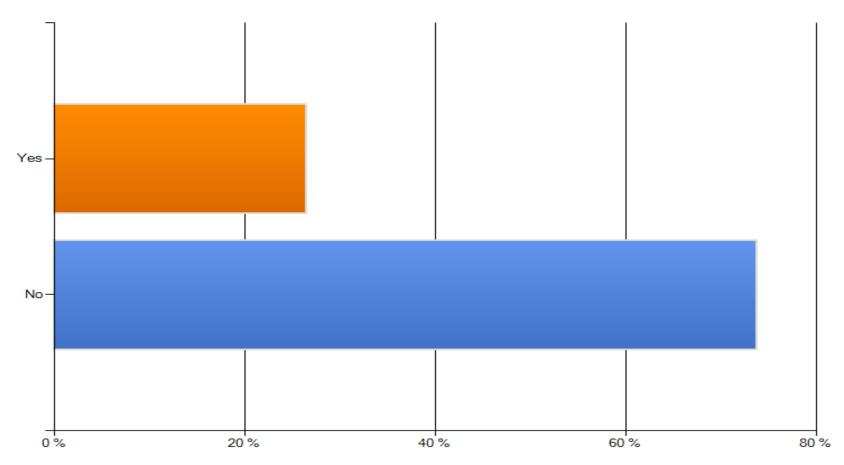
### Do you read other people's health/illness blogs?



### Have you shared your blog with family members or friends?



### Have you shared your blog with your health care provider(s)?



## Blogs shared with providers

- Less than 1 in 4 respondents shared their blogs with their healthcare providers (HCP)
- Reasons:
  - HCP wouldn't be interested
  - HCP doesn't have time
  - Want to vent
  - Concerned about judgments or repercussions to care
  - → Blog is "my" reality

## Some psychosocial themes identified

- Increased connection with others
- Decreased sense of isolation
- Increased ability to tell one's illness story to others
- Increased accountability (to self and others)
- Increased sense of efficacy
- Increased sense of purpose, meaning and understanding of illness

### Many ethical issues arise when studying blogs

- What is invasive to blog authors?
- What feels voyeuristic to you? Do you ever feel like a stalker?
- Can you register, follow, "like"?
- Can you comment?
- Can you contact them?

### Illness is replete with emotional experiences

- Can you laugh? Can you cry? Can you count your blessings?
- What do you say when someone is ill or dies?
- Acknowledgments
  - We thank Gary Klatsky, PhD, as the source of inspiration behind the initial study that led to this research. Gary, who is now deceased, wrote a blog about his brain tumor and spoke to one of the authors (LG) about the reasons he started his blog.

## More and more questions arise

- Further investigation of positive emotional and physical health outcomes
- Should blogging be recommended to newly diagnosed patients?
  - Are there patients who, based on their disease or stage of disease, would benefit from blogging but would not think to?
  - Are there differences based on type of illness, such as visible/hidden?
  - Should healthcare providers recommend starting a blog and, if so, is there an optimal time?
  - Development of educational tool to assist patients/providers in initiating a patient blog
- Is there a better mechanism to help patients locate relevant blogs?
- What can be learned about the experience of illness from analyzing patient blogs?

### Breast Cancer? But Doctor....I hate pink

Blogging my life with breast cancer, from suspicion to diagnosis to treatment. Now livin' the Stage IV Lifestyle! Terminal Cancer can be funny. Just not for very long.

Being experienced in medical procedures, I have a uniform I wear to them now: velour sweat pants, matching velour zippered jacket (essentially Juicy Couture track suit knock-offs), a tank top, and a pull-up bra, like a Coobie. I top it off with slip-on Tom's shoes. Before I leave the house, I take off all my jewelry including wedding bands. With this outfit, whatever they want off me comes off easy, putting it back on is pain-free, and whatever I get to keep on is comfy and warm. Plus, I still look presentable to the public, like I actually got dressed. Hey, if Eva Longoria wore track suits out to the store on Desperate Housewives, I certainly can to a medical waiting room. And, if need be, (and need always be) I can go straight to bed in it. Talk about your duel-need clothing. Although it was 108 on the day I went for the procedure, I really needed the jacket that came with it.

## Repository of Blogs

- Create a repository of patient blogs in which patients can search for a specific type of blog or blogger
  - Define what makes good matches based on patient needs and measures of quality (to filter out blogs promoting products or erroneous information)
  - Search for, filter, and index blogs on an ongoing basis (since the content is not static)
  - Develop a specialized search engine that returns and ranks results

## Learn from Blogs

- Help cancer patients, clinicians, and researchers to learn from blogs
  - Textual summaries of individual blogs to patients or clinicians
  - Timelines of the course of a patient's disease and treatment based on dated entries and content analysis
  - Answer questions about how cancer patients
    - react to diagnoses
    - develop coping strategies
    - experience and mitigate side effects of treatments
    - address the challenges of treatment adherence
    - other aspects of life as a cancer patient

## Next steps

- Are there successes that can be learned from?
  - Aggregation sites
    - News and travel repositories that aggregate blogs
  - Search tools
    - Dating sites
  - Technologies to "mine"
    - Increasingly used for social media
    - Sentiment analysis
    - Disease and disaster detection
- Proof of concept