

# Blogging for Health: Communicating the Experience of Illness

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# Communicating the experience of illness in writing

public

private

book

social media

journal

journal  
on  
Care-  
Pages

email

letters

blog

twitter

Facebook

Technology-  
enabled

# Blogs are powerful tools

- Many people use for variety of purposes
  - General communication and promotion
  - Within many disciplines including healthcare
- Evolved from...
  - Medical Narrative
  - Storytelling
  - Journaling
- Blogs not studied previously as vehicle for patient communication

# Patient blog “market share”

- 13% of *e-patients* write a blog about their diagnosis and treatment
  - e-patients refers to the 61% of US adults who use the Internet for health information
- Fertile field with
  - More than 133 million individuals living with chronic illness in the US
  - The popularity of blogs and other social media
  - Increased visibility on hospital and media Web sites

# Our initial interest

SATURDAY, JANUARY 10, 2009

new year

- Gary Klatsky, Professor of Psychology at SUNY Oswego, who blogged his cancer
- This was his final post



Thanks to all my family and friends for all the love and support you gave me last year that is what kept me going I love you all. I had a scan yesterday Friday 1/9/09 There is some spreading of the cancer The good news is that the Avastin 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 feel like 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: <http://garysurgery.blogspot.com/>
- A few are widely read and promoted



# Leroy Sievers, NPR

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## myCANCER



< previous post

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### I Am Not My Disease

by LEROY SIEVERS

07:24 am

July 12, 2006

E-mail

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Comments (0)

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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

“

**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.**

”

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### search my cancer

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### 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.

# Dana Jennings, New York Times

NUTRITION



Recipes for Health

HEALTH»



Patient Voices: Migraine

CANCER JOURNAL



One Man's Story of Living With Prostate Cancer



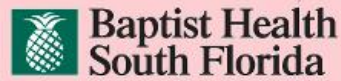
From 1 to 25 of 699 Comments

1 2 3 ... 28 Next »

1. 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 disease 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]



Mimi

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

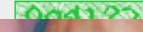
Name (required)

Mail (will not be published) (required)

Website

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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

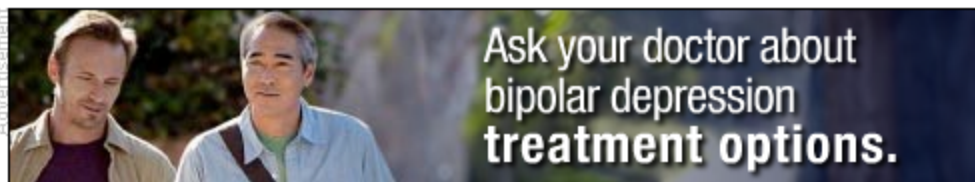
### Recent Posts

- 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 Month

### Archives



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## Live Mental

Life with bipolar disorder  
by lael8

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June 14, 2010

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# 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.”*

# Potential or perceived benefits

- From perspective of
  - Patients
  - Family and friends
  - Healthcare providers
  - Medical community

# Future directions

- Positive health outcomes?
- Recommend to newly diagnosed patients?
  - Are there patients who, based on their disease or stage of disease, would benefit from blogging?
  - Differences based on type of illness, such as visible/hidden?
- Larger study planned

# Get involved

- Dana Jennings interview: <http://lisagualtieri.com>
- CDC Health Communication, Marketing and Media Conference, Aug 2010
- Paper, handout
- Survey
- Our contact information:
  - Lisa Gualtieri ([l.gualtieri@tufts.edu](mailto:l.gualtieri@tufts.edu))
  - Pamela Ressler ([pamela.ressler@tufts.edu](mailto:pamela.ressler@tufts.edu))