

The Patient as an Active Partner

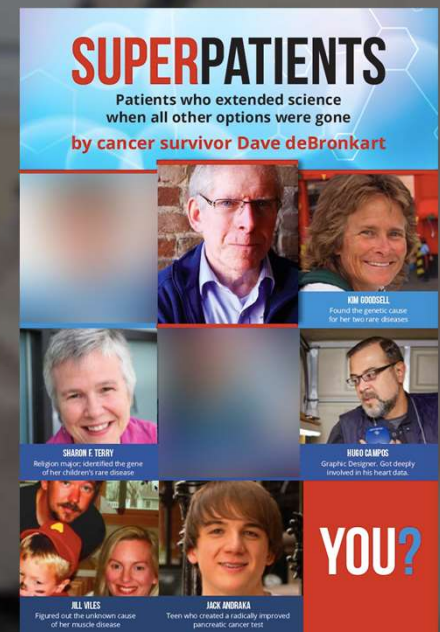
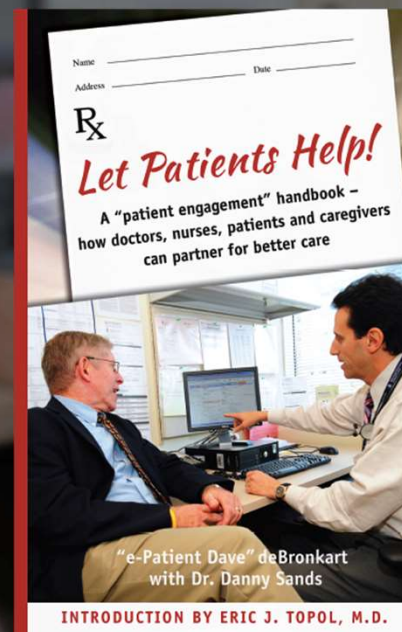
Dave deBronkart

Twitter: @ePatientDave
dave@epatientdave.com



Society for
**Participatory
Medicine**

Bringing together e-patients and health care professionals.



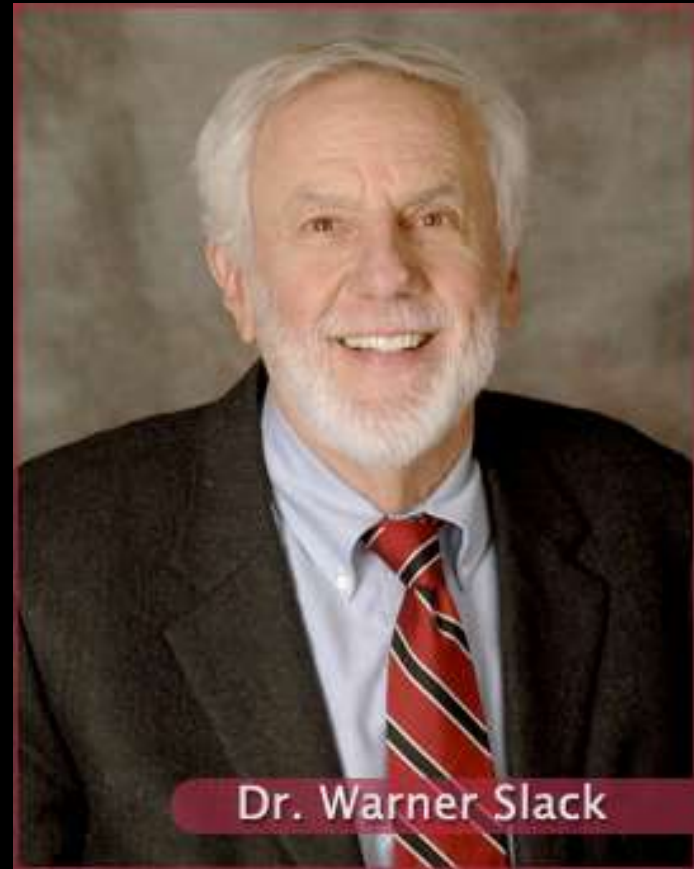
How I came to be here

- High tech marketing: data geek; tech trends; automation
- 2007: Cancer discovery & recovery
- 2008: E-patient blogger
- 2009: Participatory Medicine, public speaking
- 2010: Full time
- 2011: international
- 2012: med schools, advisory, consult
- 650 events, 26 countries, 1400 blog posts, 13 universities, 19 articles, 2 book chapters



*Informatics pioneer
Dr. Warner Slack,
since the 1970s*

**“Patients are
the most under-
used resource
in healthcare”**



**How can that be??
We don't have medical
training.**

But we do know what's
important to *us*,
and we know whether
the treatment's
solving our problem.



e-patients.net

because health professionals can't do it alone



Doc Tom said,

“e-Patients are

Equipped

Engaged

Empowered

Enabled”



Society for
**Participatory
Medicine**

Bringing together e-patients and health care professionals.

HealthLeaders

WWW.HEALTHLEADERSMEDIA.COM SEPTEMBER 2009 \$8.00

THE PATIENT OF THE FUTURE

Physicians suggest. Patients ignore. Technology alone won't bring them together. But a new relationship just might. p 16



Certifiable
Stroke Care p 33

The Art of
Balancing Risk p 47

Real-World
Bundling p 53

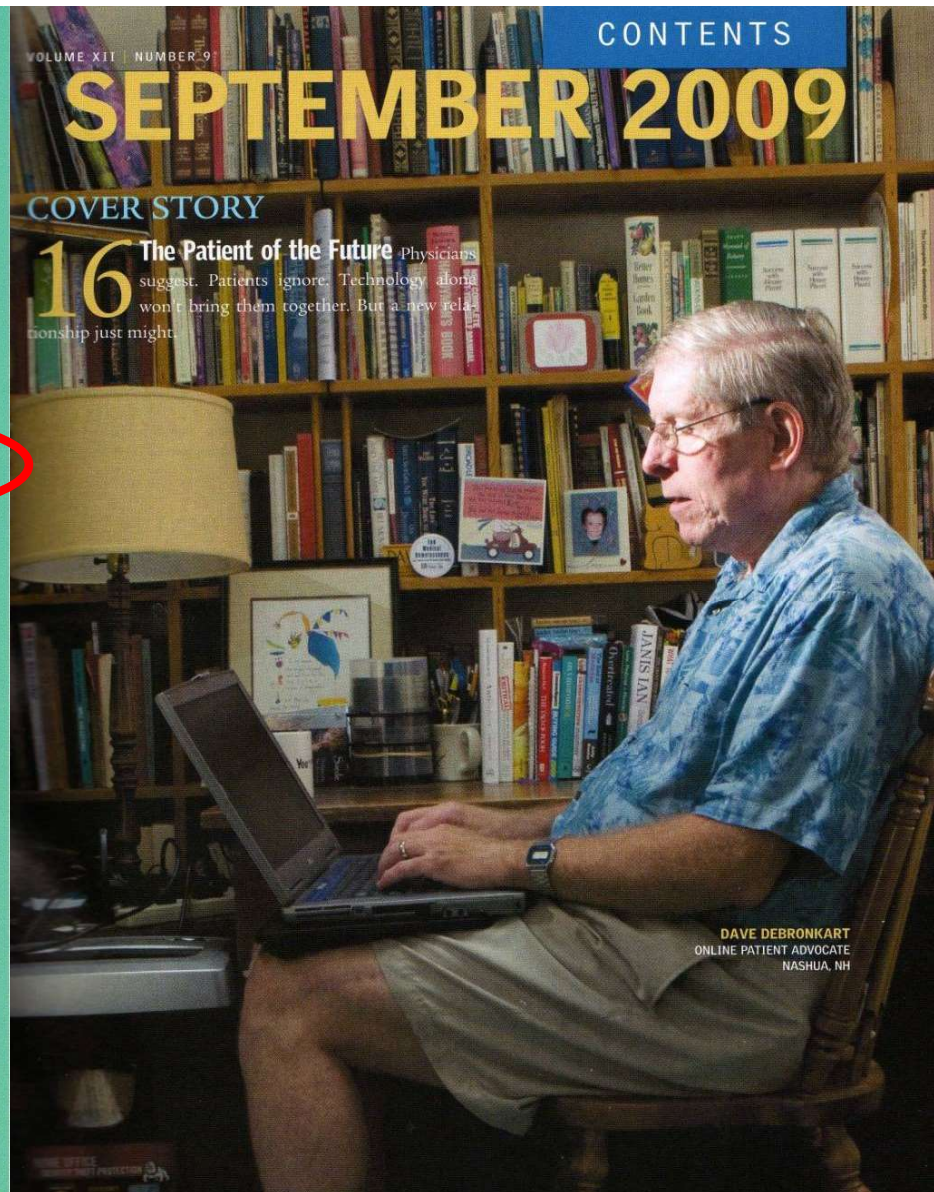
VOLUME XII | NUMBER 9

CONTENTS

SEPTEMBER 2009

COVER STORY

16 **The Patient of the Future** Physicians suggest. Patients ignore. Technology alone won't bring them together. But a new relationship just might. p 16



DAVE DEBRONKART
ONLINE PATIENT ADVOCATE
NASHUA, NH

20 PEOPLE WHO MAKE HEALTHCARE BETTER

The very essence of healthcare is to make a difference for good. At its core, this is an industry focused on making life better for people. That simplicity of mission establishes a shared grounding for the millions who work daily to deliver the best healthcare they can. In our annual *HealthLeaders 20*, we offer profiles of some who are doing just that. You can read long form versions of each of these profiles, and listen to audio interviews online by visiting www.healthleadersmedia.com/20people/.

> THE UGLY TRUTH ABOUT COST

Atul Gawande, MD

If you worked in healthcare in 2009, someone told you to read the article. Even the president of the United States held up the article as required reading for those who would understand why healthcare reform is so urgent.

Even months later, Atul Gawande, MD, wonders how his article "The Cost Conundrum" in the June 1 *New Yorker* struck a very raw nerve. Part of what gives Gawande's mass-audience writing on healthcare such heft is his blend of a physician's knowledge with a master storyteller's need to find the problem where it lives. Many had dissected the academic data on Medicare costs put out by the Dartmouth Atlas, but Gawande says that only told part of the story.

"The whole reason I wrote it is that I wasn't certain of what to make of the Dartmouth data," Gawande says. "It seemed to me that I had a second problem, which was that we didn't understand what to do about costs."

The reaction to the story was reassuring to Gawande, but not just because so many people in high places referenced it. To Gawande that the reaction was so strong was an affirmation of why he writes a story: because he doesn't fully grasp an important issue and hopes his exploration of the answers is shared.

He also takes some pride in that those who chose to use his article as a point in the ongoing healthcare reform debate came from both sides of the political aisle. "They might disagree about how you solve it, but if it helps crystallize the problems that we want reform to solve in order to make care better—not just cheaper but generally better—that is what all my work is about."

—JIM MOLPUS

> TRYING TO DELIVER MIRACLES

Dean Kamen

While still in high school, Dean Kamen was making money by designing light and sound systems

for rock bands and museums. Pretty cool. But early on in his career, the renowned inventor determined to focus on "the really important stuff that can make a big difference to people."

Much of Kamen's work is dedicated to healthcare and medical products. Among his inventions: the AutoSyringe wearable infusion pump; the Homechoice PD, a peritoneal dialysis machine; and the iBOT self-balancing wheelchair.

Kamen's latest healthcare breakthrough is a robotic prosthetic being developed for the military. The DEKA Arm virtually reacts to the user's thoughts, an arm and hand that has the sensitivity to distinguish among and handle objects as diverse as a razor blade and a grape, all the while using a range of motion akin to a healthy, human arm.

Kamen lives at a hilltop estate in Bedford, NH. He often pilots his own helicopter from there to his DEKA Research and Development Corp., which employs about 300 in the city of Manchester, NH.

"I get passionate about trying to solve a problem. I've got some really, really smart people here that will jump all over trying to deliver miracles. It's fun, it's exciting, and when it works, it makes us feel pretty good about ourselves and the future."



Gawande



Kamen



deBronkart

The theme of personal responsibility is also essential to Kamen's vision. "We're going to have to stop assuming we are recipients of magic from them— whoever the 'them' is, whether it's the insurance company or the government or your doctor. There's no 'them' out there. It's going to be a world where people are responsible, they're not recipients, they're customers, they're patients, and they're going to be involved in preventing diseases and hopefully treating them more effectively than passively being the recipient of a process."

—BOB WERTZ

> PATIENT ENGAGEMENT ADVOCATE

Dave deBronkart

Dave deBronkart is the quintessential engaged patient consumer the likes of whom—depending on your viewpoint—is either an anomaly or an inevitability.

In 2007, deBronkart was diagnosed with stage four kidney cancer. His Boston-based physician,

Daniel Sands, MD, introduced him to the cancer support site Acor.org, which has an online chat room for kidney cancer patients.

Soon after, deBronkart was invited to join a meeting of ACOR's e-patient scholars working group—of which Sands was a member. At that time, deBronkart became an active blogger on e-patients.net and took on the online handle that many know him by: ePatientDave.

"My life just pivoted like on a railroad turntable at that moment."

Now deBronkart often works late into the night, spreading his patient empowerment message in chat rooms, on blogs, via Twitter, and in other forums. More recently, deBronkart and Sands became co-chairs of the board of directors for the Society for Participatory Medicine, another e-patients.net offshoot. Through all these venues, deBronkart's main message reverberates: Patients have the right to know and pursue their options. He believes that "great doctors saved my life," but patients can and should contribute to their own care.

As for whether or not engaged patients are an anomaly or an inevitability? "All I can say is we're

spreading the word," says deBronkart. "And sooner or later everybody will be headed to our party."

—GIENNA SHAW

> EARLY ADVOCATE FOR PATIENT E-MAIL, ENGAGEMENT

Daniel Sands, MD

A decidedly engaged physician, Daniel Sands, MD, says, "If I had my druthers, I would take care of only patients who are engaged." A physician at the 621-bed Beth Israel Deaconess Medical Center in Boston, Sands says, "I've always been interested in what we now call participatory medicine. It's the way I like to practice."

From writing guidelines for communicating with patients via e-mail to helping to develop clinical decision support systems and patient portals, Sands is also a huge advocate of using technology to improve the patient experience. And he can only be described as an early adopter.

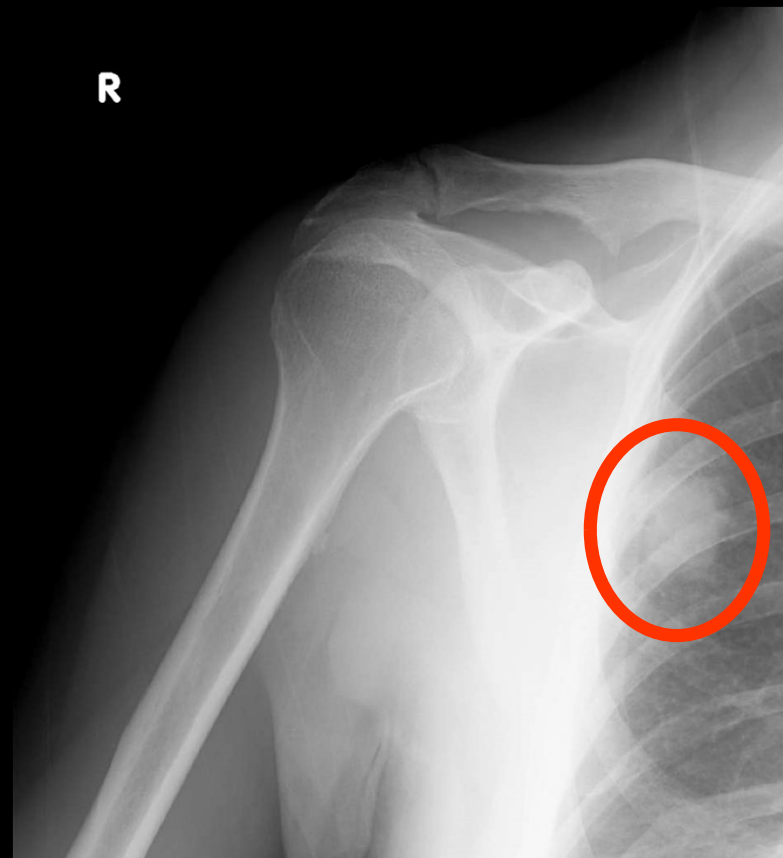
Me? An indicator of the future??

- Who's getting online:
 - 1989: Me (CompuServe sysop)
 - 2009: 83% of US adults (Pew)
- Who's romancing online:
 - 1999: I met my wife (Match.com)
 - 2009: One in eight weddings in the U.S. met online
 - 2011: One in five couples met online



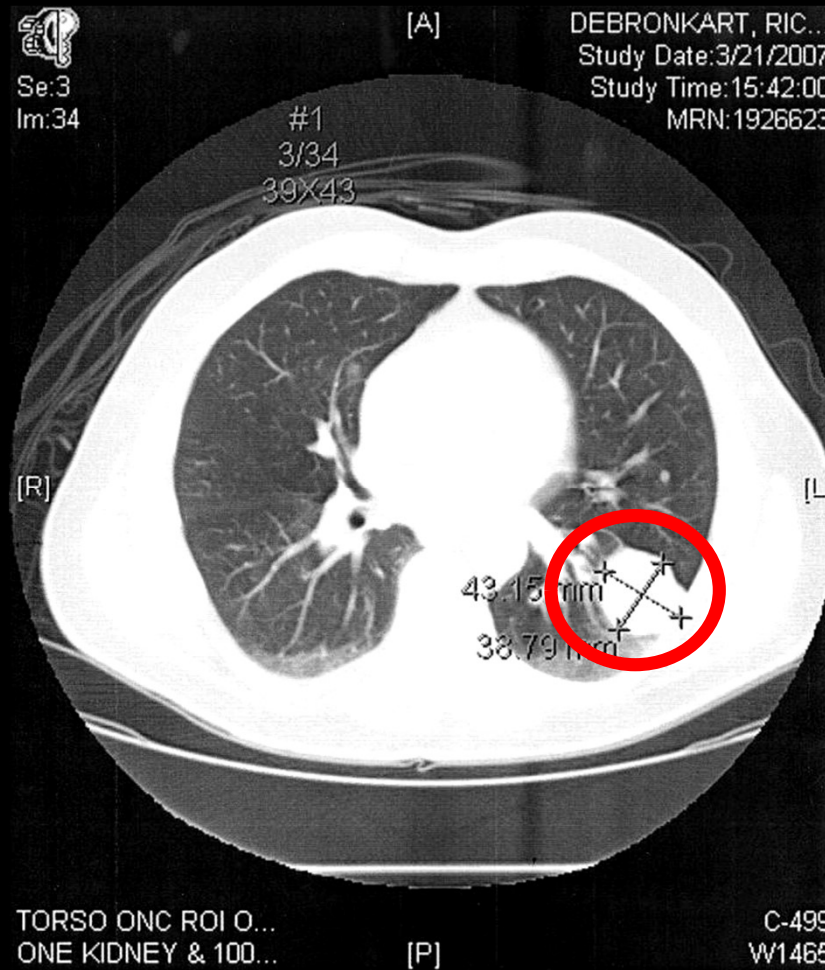
2007: My “Incidental Finding”

Routine shoulder x-ray, Jan. 2, 2007



*“Your shoulder
will be fine ...
but there's
something
in your lung”*

One of my five lung “mets”



“My doctor prescribed ACOR”

(Community of my patient peers)

acor.org
Association of Cancer Online Resources

The free online lifeline for everyone affected by cancer & related disorders

Home Dictionary Help Site Map

Find a mailing list Search

WELCOME
Association of Cancer Online Resources

ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment.

ACOR offers access to mailing lists that provide support, information, and community to everyone affected by cancer and related disorders.

- ▶ **MAILING LISTS**
ONLINE COMMUNITIES
- ▶ **SUPPORT & RESOURCES**
- ▶ **TYPES OF CANCER**
BY A-TO-Z LIST
- ▶ **TREATMENT OPTIONS**
CURRENT TREATMENTS
- ▶ **CLINICAL TRIALS**
EXPERIMENTAL TREATMENTS
- ▶ **PUBLICATIONS**
CANCER-RELATED BOOKS
- ▶ **PARTNERSHIPS**
ALLIANCES & FRIENDS
- ▶ **HELP ACOR**
DONATIONS & VOLUNTEERS

News

Fat tissue-derived hormone leptin increases e-cadherin expression, obesity-breast cancer link noted
Being obese increases the risk of breast cancer in post-menopausal women, shortens the time between return of the disease and lowers overall ...
Apr 29, 2007
[\[Full Story\]](#)

What's New

Please Note: Mar 26, 2007 Update: We have started

My patient peers told me:

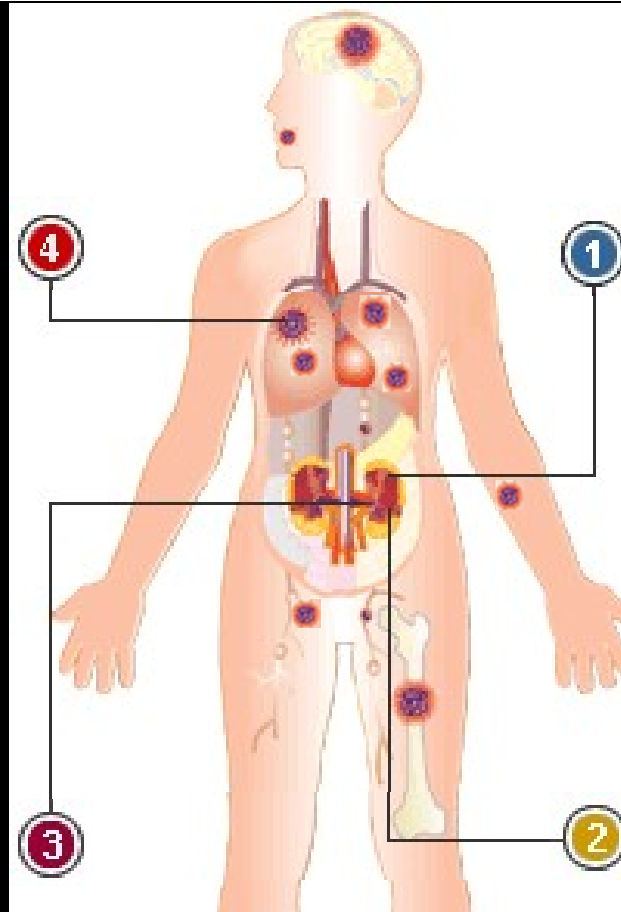
- Welcome to the club nobody wants to join. We know what it's like.
- This is an uncommon disease – get to a hospital that does a lot of cases
- There's no cure, but HDIL-2 sometimes works.
 - When it does, about half the time it's permanent
 - The side effects are severe.
- Don't let them give you anything else first
- Here are four doctors in your area who do it

My patient peers told me:

- Welcome to the club nobody wants to join. We know what it's like.
- This is an uncommon disease – get to a hospital that does a lot of cases
- There's no cure, but HDIL-2 sometimes works.
 - When it does, about half the time it's permanent
 - **The side effects are severe.**
- Don't let them give you anything else first
- Here are four doctors in your area who do it

Classic Stage IV, Grade 4 Renal Cell Carcinoma

Illustration on
the drug company's
web site



**Median Survival:
24 weeks**

**Patients are the
ultimate stakeholder.**

(They have more “at stake” than anyone)

Facing death

My mother

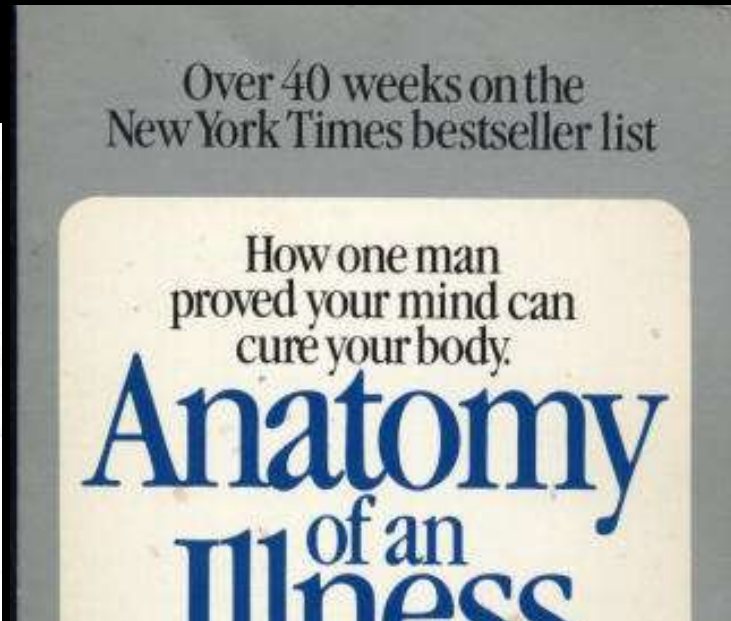
My daughter

**After the shock
you're left with the question:**

What are my options?

What can I do?

Norman Cousins



The basic theme of this book is that every person must accept a certain measure of responsibility for his or her own recovery from disease or disability.

Cousins

Me 21st Century



1975 - 1976
SNL



THE COMPLETE
FIRST SEASON

Laugh ... and Sing



Laugh & Sing Eat Like a Pig

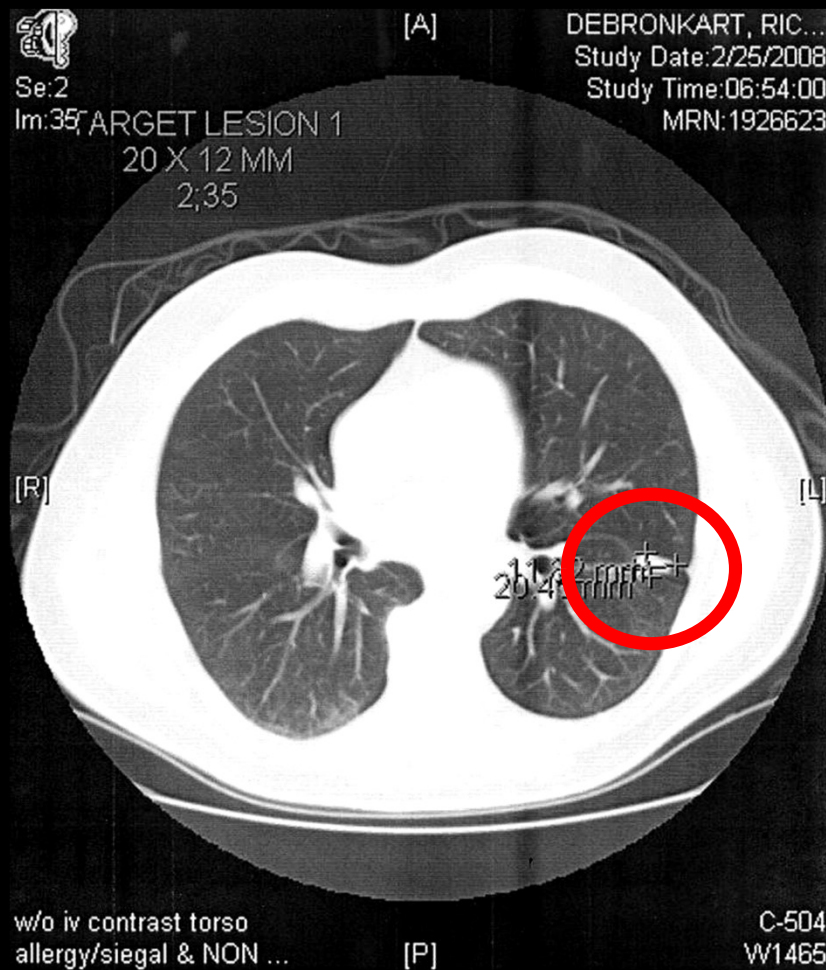
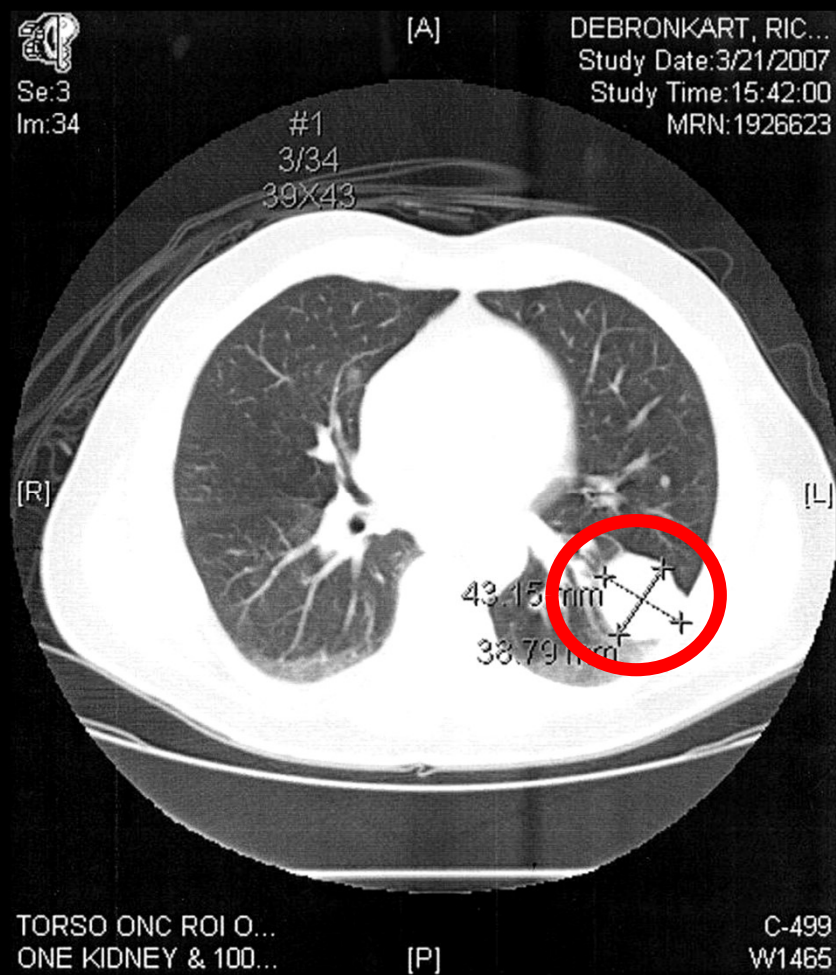


**How an empowered patient beat Stage IV cancer
(and what healthcare can learn from it)**

Introductory essays by Dr. Danny Sands, Paul F. Levy, and Matthew Holt

**"In my list of greatest personal reads"
— James B. Conway, Institute for Healthcare Improvement**

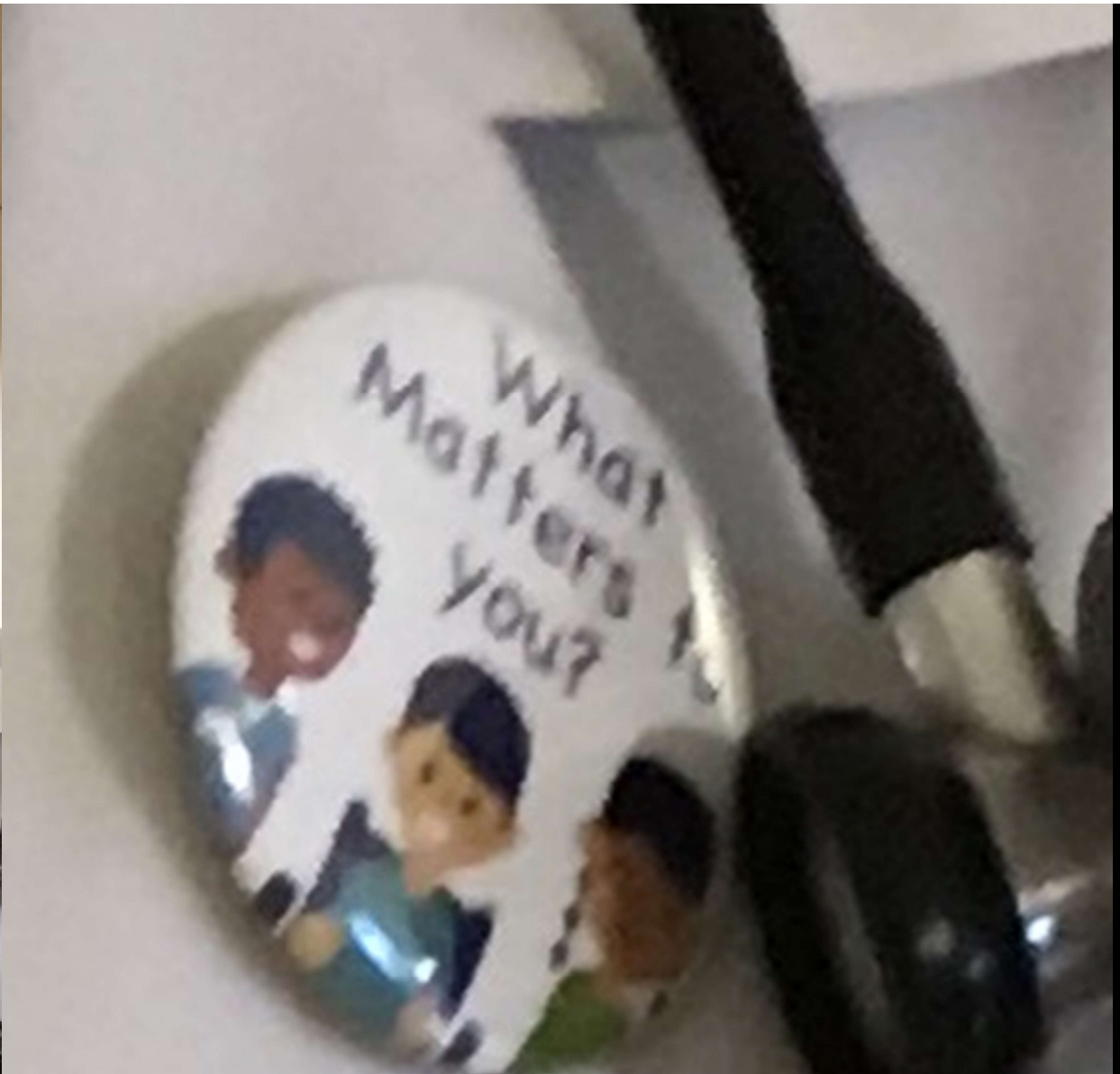
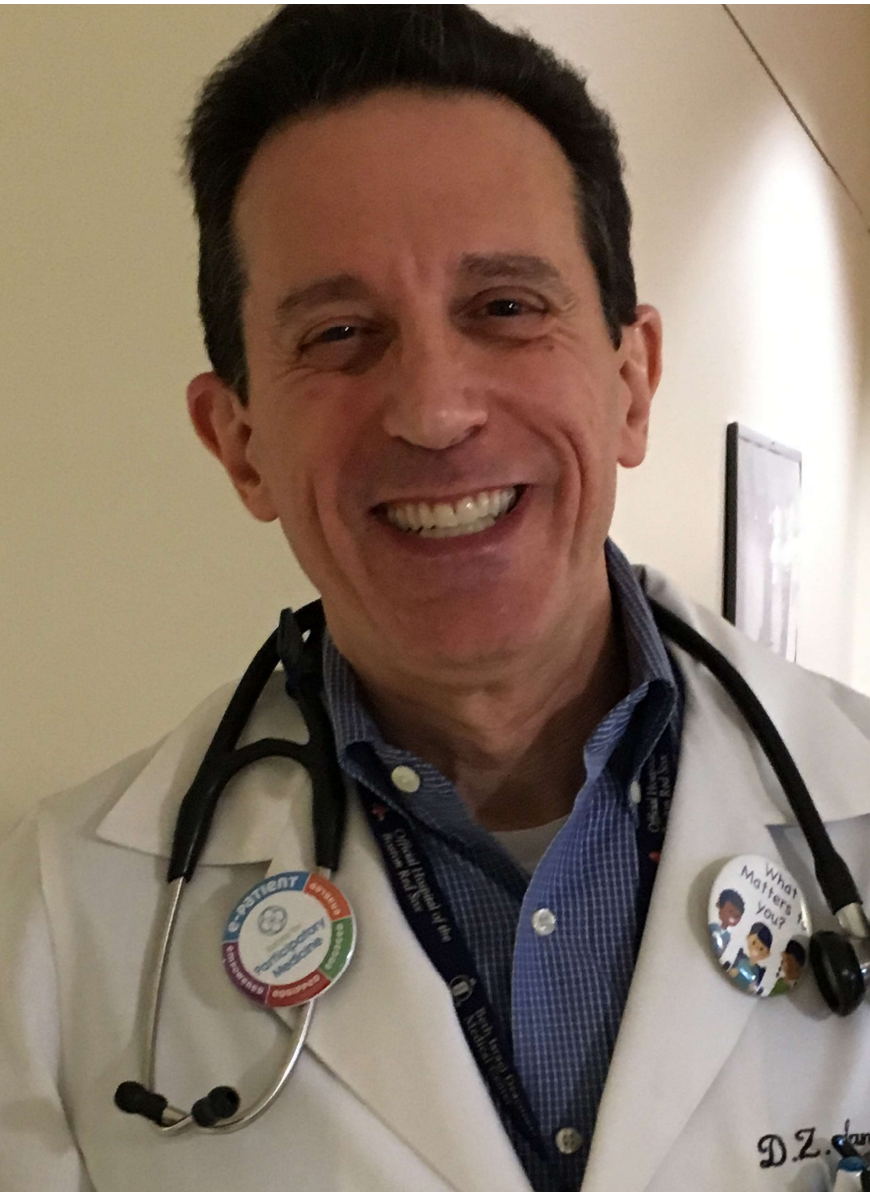
Surgery & Interleukin worked – in six months



ACOR's practical information may have saved my life

As a responsible engaged patient, knowing that IL-2's side effects might kill me, I sought to prepare myself. First I sought authoritative sources; there I found dry facts: "Side effects are often severe and rarely fatal, and include . . ." I thought, "What am I supposed to do with that?" and turned to my peers on ACOR. I asked, "You who've done this—what was it like? What do I need to know?" From them I received 17 firsthand stories—a wide range of experiences. I felt prepared—and today Dr McDermott says, "You were really sick. I don't know if you could have tolerated enough medicine if you hadn't been so well prepared." In this case

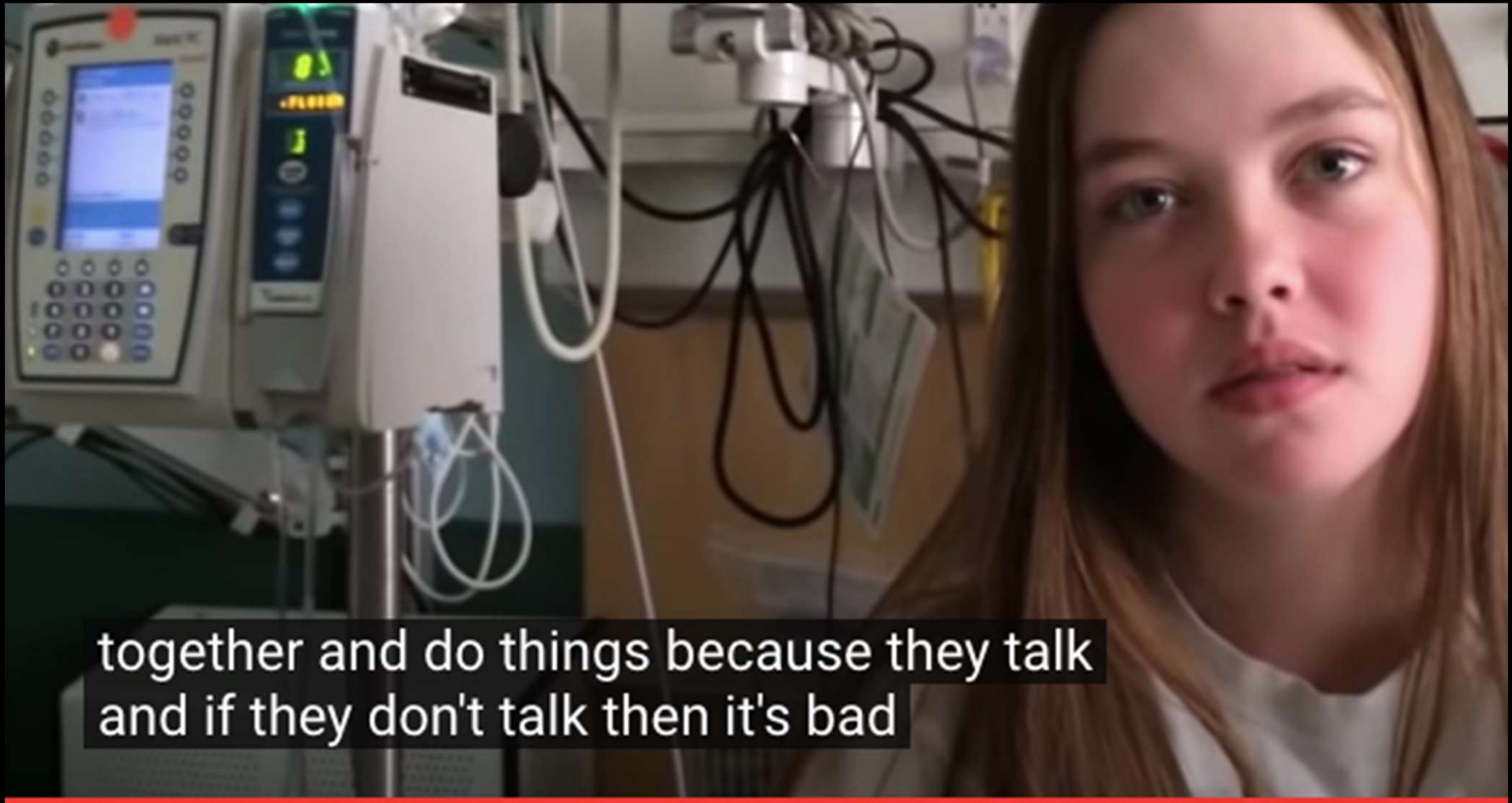
He says
we did it together.



**“Patients know
what patients want to know”**

“I am the patient and I need to be heard”

- <https://www.youtube.com/watch?v=BqFfRiyW07I>



together and do things because they talk
and if they don't talk then it's bad

Giving Patients an Active Role in Their Health Care

by [Len Schlesinger](#) and [John Fox](#)

NOVEMBER 21, 2016



SAVE



SHARE



COMMENT



TEXT SIZE



PRINT



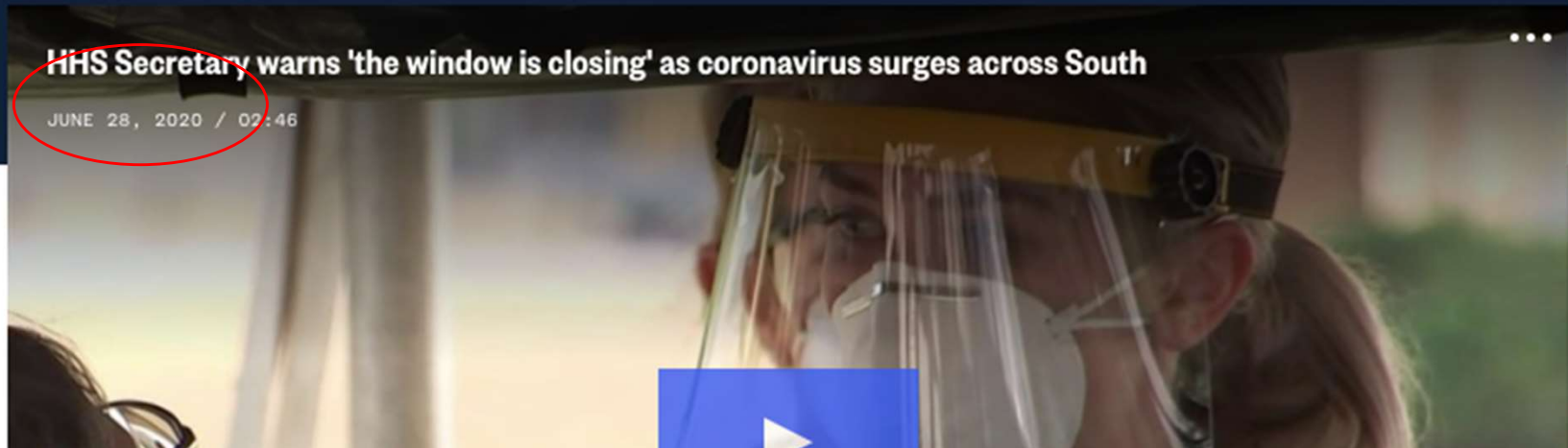
\$8.95
BUY COPIES



As payment and care delivery models shift in the United States from episodic, fee-for-service care toward population health and value-based reimbursement, health care leaders are focused more than ever on patient engagement as a key to driving down costs and improving outcomes. And yet, as so many of us know who have attempted to manage our own care or tend to sick family members, the U.S. health care system rarely feels like it's

Some COVID-19 patients aren't getting better. Major medical centers are trying to figure out how to help.

"What we need is more research to explain where the symptoms are coming from," one expert said.



MIT
Technology
Review

Covid-19 “long haulers” are organizing online to study themselves

Slack groups and social media are connecting people who've never fully recovered from coronavirus to collect data on their condition.

by **Tanya Basu**

August 12, 2020

Gina Assaf was running in Washington, DC, on March 19 when she suddenly couldn't take another step. “I was so out of breath I had to stop,” she says. Five days earlier, she'd hung out with a friend; within days, that friend and their partner had started showing three classic signs of covid-19: fever, cough, and shortness of breath.



May 2021



NIH Strategic Response | Funding | Testing | Treatments and Vaccines |

May 20, 2021

NIH Plans Research on “Long COVID”

The new PASC Initiative will look at long-term symptoms of COVID-19

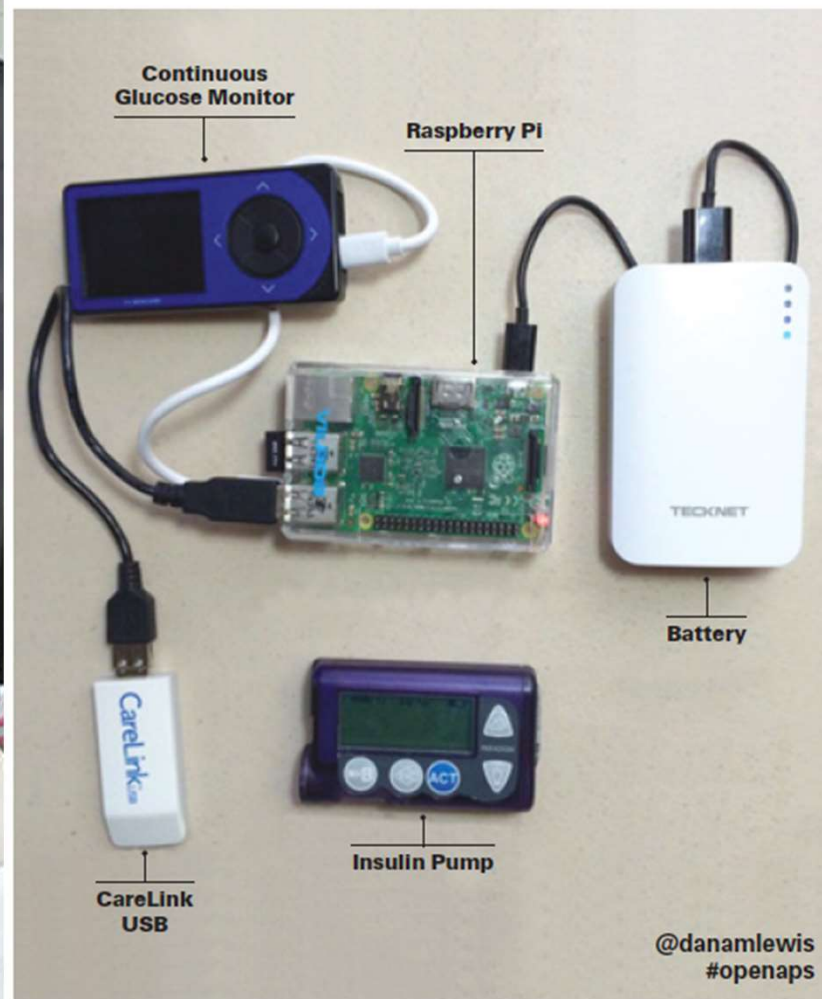


Superpatient: @DanaMLewis

with @ScottLeibrand
and the whole
#OpenAPS #DIYPS
#NightScout crowd

A DIY ARTIFICIAL PANCREAS

The artificial pancreas that type 1 diabetes patient Dana Lewis and her co-innovators developed for themselves used an off-the-shelf microcomputer to connect commercially available continuous glucose monitors with commercially available insulin pumps.



Traditional innovation

NOT LIKE THIS



1

2

3

4



Traditional innovation

NOT LIKE THIS



1



2



3



4

LIKE THIS



Start Here



1



2



3



4



5

User-driven innovation

@DanaMLewis

Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions

Viet-Thi Tran, Caroline Barnes, Victor M. Montori, Bruno Falissard and Philippe Ravaud

Abstract

Background

Management strategies for patients with chronic conditions are becoming increasingly complex, which result in a burden of treatment for patients. To develop a Minimally Disruptive Medicine designed to reduce the burden of treatment, clinicians need to understand which healthcare tasks and aggravating factors are responsible for this burden. The objective of the present study was to describe and classify the components of the burden of treatment for patients with chronic conditions from the patient's perspective.

Methods

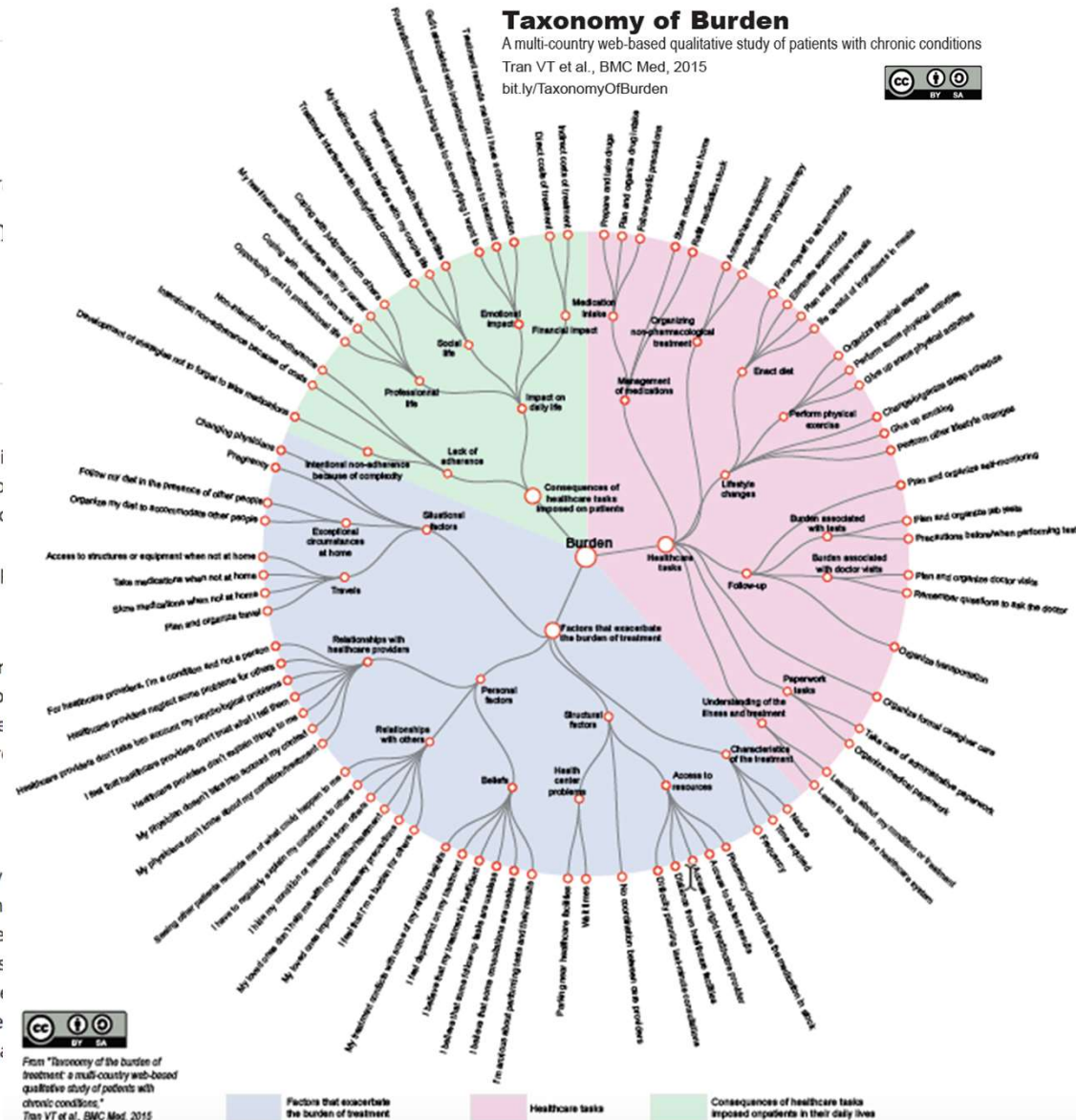
We performed a multi-country qualitative study using an online survey and a purposive sampling strategy to select English-, French-, and Spanish-speaking participants with different chronic conditions. Participants were recruited by physicians, patients' associations, advertisement on social media, and 'snowballing'. The data were analyzed by i) manual content analysis with a grounded theory approach, coded by two researchers; and ii) automatic textual analysis by Reinert's method.

Results

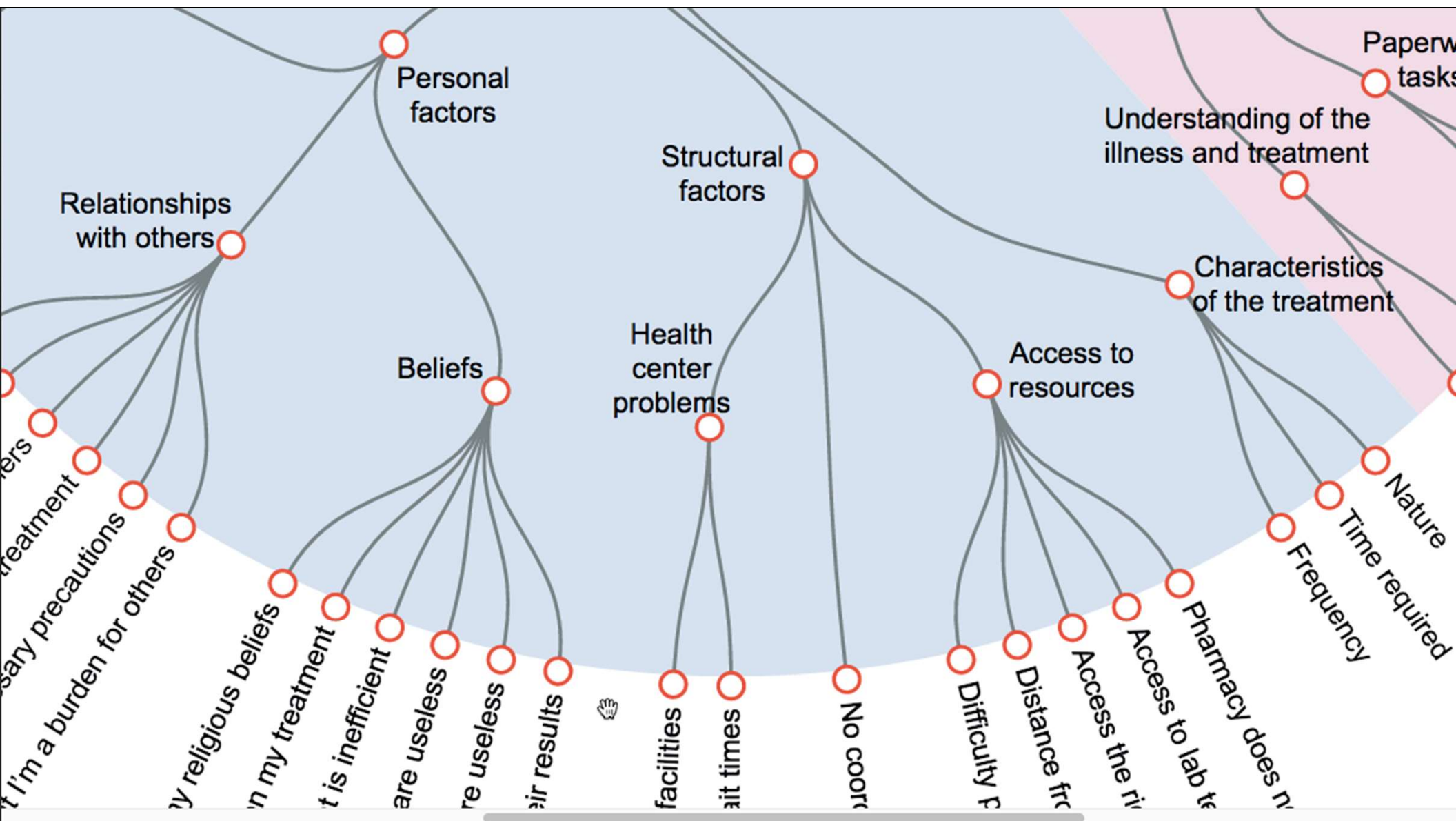
Between 2013 and 2014, 1,053 participants from 34 different countries completed the online survey, generating 408,625 words. Results from both analyses were synthesized in a taxonomy of the burden of treatment, described i) the tasks imposed on patients by their diseases and by their healthcare system (e.g., medication management, lifestyle changes, follow-up, etc.); ii) the structural (e.g., access to healthcare resources, coordination between care providers), personal, situational, and financial factors that aggravated the burden of treatment; and iii) patient-reported consequences of the burden (e.g., poor adherence to treatment, financial burden, impact on professional, family, and social life, etc.). Our findings may not be applicable to patients with chronic conditions who differ from those who responded to our survey.

Taxonomy of Burden

A multi-country web-based qualitative study of patients with chronic conditions
 Tran VT et al., BMC Med, 2015
 bit.ly/TaxonomyOfBurden



From "Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions." Tran VT et al., BMC Med, 2015



Personal factors

Relationships with others

Beliefs

Health center problems

Access to resources

Characteristics of the treatment

Understanding of the illness and treatment

Paperwork tasks

ers

treatment

nary precautions

I'm a burden for others

ly religious beliefs

n my treatment

t is inefficient

are useless

re useless

air results

facilities

ait times

No coord

Difficulty f

Distance fro

Access the ni

Access to lab te

Pharmacy does n

Frequency

Time required

Nature

Dutch IVF program had an insane idea

- Give patient couples a wiki, and six months to talk
- “We’ll give you anything you decide – your top ten choices.”



Top things IVF patients asked for

- More attempts at fertilization
- Empathy from my doctor, not just technical or financial information.
- Separate waiting rooms for pregnant couples and those who aren't yet

Participatory Medicine is a movement.

Visionary physicians have said since the 1970s that patients are the most under-used resource in healthcare. Today, empowered by the Web and digital health, clinicians and patients in the Society for Participatory Medicine have developed this set of principles and practices - five matching promises - to enable adoption of this new model of practice and self-care.

Join us. Sign the manifesto, and spread the word.

SignTheManifesto.org



I pledge my commitment to the Participatory Medicine Manifesto and promise to do the following:

As a healthcare professional I will:

As a patient or caregiver I will:



2.8 e-Patient Years in Pictures...

December 2006



October 2007



May 2009



Personally, *I love medicine.*

“ I beat cancer so I
could dance with my
daughter at her
wedding. ”

-Dave deBronkart





How might we rethink
how *care* is achieved,
so people remember us
for bringing joy and hope
to their families?

Empowered Patients as Active Partners: A new model for the best care

Dave deBronkart

Twitter: @ePatientDave
dave@epatientdave.com



Bringing together e-patients and health care professionals.

