A Perspective on Transparency

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Aligning Quality and Value in Hematopoietic Cell Transplantation
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Disclosures

- General internist, MPH, decades of administrative work
- No financial relationships, volunteer for OpenNotes
- Accept “markets” as a reality but market settings are often not a “level playing field.”
- Advertising and promotion are an effective means of providing biased information to consumers leading to frequent overuse or misuse.
- Consumers need independent, scientific information to make optimal selections.
- 2 personal experiences
HEALTH CARE ADVERTISING

NOW

SOMEDAY??

Healthcare in a land called PeoplePower:
nothing about me without me

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Abstract

In a 5-day retreat at a Salzburg Seminar attended by 64 individuals
from 29 countries, teams of health professionals, patient advocates,
artists, reporters and social scientists adopted the guiding principle
of ‘nothing about me without me’ and created the country of
PeoplePower. Designed to shift health care from ‘biomedicine’ to
‘infomedicine’, patients and health workers throughout People-
Power join in informed, shared decision-making and governance.
Drawing, where possible, on computer-based guidance and
communication technologies, patients and clinicians contribute
actively to the patient record, transcripts of clinical encounters are
shared, and patient education occurs primarily in the home, school
THE DAY I STARTED LYING TO RUTH
PETER BACH MD
NEW YORK MAGAZINE
MAY 2014

“I don’t want my doctor knowing something about me that I don’t.”
Ruth Bach

Transparency

• Trust
  – Conflicts of interest—financial and academic
• Evidence based benefits and risks
• Performance measurement
• Patient experience
• Cost/Price transparency
• OpenNotes
Conflicts of Interest

• Large databases now make financial relationships with industry easy to identify
  – But fuzzy definitions of research versus marketing activity confuse
• NEJM/Pharmascolding
• Academic/intellectual conflicts though likely more powerful

Presentation on US Hospital Websites of Risks and Benefits of Transcatheter Aortic Valve Replacement Procedures
JAMA Internal Medicine, January 12, 2015

• Review of websites of 317 hospitals participating in STS/ACC TAVR registry
• 262 had web pages with TAVR information
• 260 had benefit information
• 69 had risk information
• Benefits quantified on 97, risks on 12 (P<.0001)
• RCT shows TAVR has 2x risk of stroke of Open AVR
Voluntary Disclosure

- Informing/encouraging/confirming
- Coordinating
  - Especially with marketing and communications
- Volunteers likely (but not always) better performers
- Unlikely selection explains the better performance of volunteers
- Describing the non participants
  - Never participants
  - Drop outs
Preparing for Public Disclosure

- NQRN
- Great data
- Reporting unit names, locations
- Consistency with other sources
- Presentation issues
  - Tiering
  - Symbols
  - Composites

Our Results

- 10 publications presenting physician performance
- High readership, high web traffic, increased news stand sales
  - All indication of demand
- NO data errors
- Name errors
- Major reader criticism—want results by individual physician
Patient Experience in Health

- Scientific approach or anecdotal (user reviews)
- Number of insurers, hospitals, doctors are a major challenge even with millions of respondents
- Hospital and health insurance CAHPS works well for us
- And so could doctors but a challenge
  - Directory a challenge
  - Collection costs substantial
  - Uniform approach that someone can afford??
  - Data at practice site and individual doctor level
  - User reviews tough competition
User Reviews at CR

• There is now a regular report that identifies products with significant disagreement between user reviews and CR ratings
• CR staff review those user reviews to determine if a reevaluation of performance measurement methods is needed, if the ratings should change, or other steps needed.
• CR acknowledges those differences on the ratings web page and reports it is trying to determine the reason for the discrepancy.

Conclusions

• Patient/consumer experience is a must for a complete sense of a product or service
• Robust physician experience surveys at an individual or even practice site level for the whole country are a huge challenge
• “Hello CR. Are you listening to our reviews.”
• We cannot ignore user reviews. They measure real consumer experience. They are affordable. They complement survey results.
Cost/Price Transparency

- Brill/Time Magazine
- Rosenthal/NY Times
- Obama transparency policies
- HealthcareBlueBook  
  - 5x variation in same market
- FairHealth
- Castlight
- Guroo.com & HCCI
- State legislation  
  - Population data versus individually actionable data

What is OpenNotes?

- Patients invited to review their providers’ visit notes through secure patient portals
- Each patient notified automatically via e-mail message when a note has been signed…and reminded to review it before their next scheduled visit
- “OpenNotes” is an initiative to give patient’s access to their EHR notes via the internet. Not a specific vendor product or software.
- Started with a research and demonstration project in 2010, involving more than 100 PCPs and 20,000 patients in Boston (BIDMC), rural Pennsylvania (Geisinger), and the Seattle inner city (Harborview)

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3 Overall Questions

- Does OpenNotes help patients become more engaged in their care?
  - YES

- Is OpenNotes the straw that breaks the doctor’s back?
  - NO

- After living with this transparency, do patients and doctors want to continue?
  - YES, virtually 100%

Kaiser Permanente Northwest:
Early information on implementation

- Traffic to portal to review visit information up 400%
- MD email traffic flat
- Rare concerns from patients about care
- ¼ of 1% of notes are hidden by providers
- Mental health providers excluded
- Adolescents (13-18) excluded
- 7,000 notes per day now available to patients.
THANK YOU

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