Plenary Speaker

Mark Lewis, MD
THE SECOND COMING OF THE GUTENBERG PRESS: DIGITAL DISSEMINATION OF INFORMATION TO PATIENTS AND PHYSICIANS

Mark A. Lewis, M.D.
SWOG Fall Meeting
Plenary II
October 4th, 2019
THE PAST AS PROLOGUE

• From the fifteenth century onward, the printed word became the primary vehicle for high-integrity transmission of information.

But ...

• Means of production were controlled by a select few
• Acquisition of knowledge required substantial resources
• Ink as a medium of programmed obsolescence

European Output of Printed Books ca. 1450–1800
THE PACE OF PROGRESS

Moore's Law is Alive and Well!
Transistors per Square Millimeter by Year
THE PLUMMETING COST OF MEMORY

- 1957: storage cost of one megabyte = $411,041,792 (transistor flip-flop)
- 2019: storage cost of one megabyte = $.0027 (1/6.56^{12} of 1957 prices)
- 2023: projected storage cost of one terabyte = < $10
THE ELECTRONIC MEDICAL RECORD

INPATIENT

Across all hospital types, more than 95% have certified EHR technology
2017

- Large: 99%
- Medium: 97%
- Small Urban: 95%
- Critical Access: 93%
- Small Rural: 93%

OUTPATIENT

EHR adoption has more than doubled since 2008
2017

- Any EHR
- Basic EHR
- Certified EHR
CLINICAL DECISION SUPPORT

Computable biomedical information + patient-specific data + reasoning mechanism = CDS

~7% of electronic prescriptions generate alerts, with a 76% override of allergies and a 91% override of drug-drug interactions

THE PHYSICIAN AS HUNTER-GATHERER OF DATA

• Physical print quickly becomes outdated & occupies space

• Number of books that can be held on a 256GB iPhone: 192,000 (1 day for ~500 years)

• ‘Information paradox’: the volume of sources available has made it increasingly difficult to find relevant facts when needed

• Search engines have become vital to the sorting process
GOOGLE AS ANATHEMA TO OUR ARCHETYPE

“William Osler,” I offered, “must be turning over in his grave. You googled the diagnosis?”

Where does this lead us? Are we physicians no longer needed? Is an observer who can accurately select the findings to be entered in a Google search all we need for a diagnosis to appear, as if by magic? The cases presented at clinicopathological conferences can be solved easily; no longer must the discussant talk at length about the differential diagnosis of fever with bradycardia. Even worse, the Google diagnostician might be linked to an evidence-based medicine database, so a computer could e-mail the prescription to the e-druggist with no human involvement needed. The education of house staff is morphing into computer-search techniques. Surely this is a trend to watch.
A Wolters-Kluwer survey asked ~300 AMA member physicians: “How often do you use the following sources to gain information used to diagnose, treat, and care for patients?”

<table>
<thead>
<tr>
<th>Source</th>
<th>Frequently</th>
<th>Occasionally</th>
<th>Rarely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional journals</td>
<td>68%</td>
<td>25%</td>
<td>7%</td>
</tr>
<tr>
<td>Colleagues</td>
<td>60%</td>
<td>32%</td>
<td>7%</td>
</tr>
<tr>
<td>General browsers (Google, Yahoo)</td>
<td>46%</td>
<td>32%</td>
<td>14%</td>
</tr>
<tr>
<td>Conferences and events</td>
<td>42%</td>
<td>44%</td>
<td>12%</td>
</tr>
<tr>
<td>Online free services (WebMD, MayoClinic.com)</td>
<td>42%</td>
<td>34%</td>
<td>15%</td>
</tr>
<tr>
<td>Professional associations/societies</td>
<td>40%</td>
<td>35%</td>
<td>19%</td>
</tr>
<tr>
<td>Medical reference books</td>
<td>37%</td>
<td>38%</td>
<td>21%</td>
</tr>
<tr>
<td>Online subscription services (UpToDate, Ebsco)</td>
<td>36%</td>
<td>31%</td>
<td>16%</td>
</tr>
<tr>
<td>Medical/drug sales reps</td>
<td>33%</td>
<td>41%</td>
<td>18%</td>
</tr>
</tbody>
</table>

• Publicly available since June 1997

• Evolved from:
  • Index Medicus – a monthly guide to medical articles maintained since 1879 by the National Library of Medicine
  • Medical Literature Analysis and Retrieval Systems (MEDLARS) – launched in 1964 and was the first large-scale computer-based retrospective search service available to the general public
  • MEDLINE = MEDLARS Online; organized by Medical Subject Headings (MeSH), including publication type

• Primary user community is professional
NOT A SEARCH ENGINE OPTIMIZED FOR EVERYONE

THE RISING TIDE OF INFORMATION

4.6 million articles in total!

Volume of PubMed articles on "cancer" over SWOG's history
CITATION YIELD FROM PUBMED SEARCHES

Half are “all or nothing”
TRENDS IN PUBMED USAGE

• Over 80% of users only browse and click results on the first page (~30% on the top ranked citation)

• Clickthrough from abstract to full text is ~30%

• Over 20% of PubMed usage now occurs on mobile platforms

DISCERNMENT IN THE DELUGE

“Some people have questioned the role of medical journals in this age of easy access to information. We think that, on the contrary, easy access to unvetted information … [makes] the journals’ work more valuable, not less. With so much medical content available on the Internet and with more accumulating every day, no one can keep up with the flood of ideas and data.

What health professionals want and need is a trusted information source that can winnow the key kernels of new clinical information from the mountains of associated chaff.”

UP TO DATE

Founded in 1992 by Dr. Burton Rose, beginning as the electronic conversion of a nephrology textbook he had authored.

Content experts author review articles that are iteratively updated.

1,000,000 topics viewed daily, with estimates of 30% change upon decision-making per view.

Intended to be a point-of-care resource, with deliberately concise recommendations made to guide treatment.
STRONG VS. WEAK

• A 2017 analysis found 9451 GRADEs within UpToDate across 2971 topics (of which 475 were oncologic in subject matter)

• The majority of recommendations on UpToDate are weak (6501, 68.8%)

• Of strong recommendations, the majority are based on at best moderate certainty of effect estimates

• Discordance between strength of recommendation and magnitude of benefit may be warranted in cases where there is surety about the cost/harm of an alternative

• Narrative presentation of recommendations results in a free text structure where explicit risk/benefit analyses and even citations might be omitted

The Traditional Process: Phone a friend

Problems with this:

1) The value of knowledge exchanged depends on the your network

2) Valuable experiential knowledge from strong networks are not documented and shared with the community.

Slide courtesy of Dr. Nadine Housri, TheMedNet
Bring the existing Q&A process in medicine online
Give clinicians access to strong expert networks

Slide courtesy of Dr. Nadine Housri, TheMedNet
THE MEDNET COMMUNITY HAS GROWN TO OVER 9,300 ONCOLOGISTS

- > 90% of all US Radiation Oncologists from over 700 institutions
- > 35% US Medical Oncologists
- > 30% US Gynecologic Oncologists
- 500+ academic oncologists from every major cancer center have answered questions

Slide courtesy of Dr. Nadine Houari, TheMedNet
Twitter

- Currently the dominant digital platform for MDs to engage one another and the public
- Means of curation and contribution
- Virtual conference attendance
VISUALIZING EXCHANGES AT MEETINGS
Hashtag ontology

Breast cancer advocates had started breast cancer social media (#bcsm) in 2011

Brain tumor social media (#btsm) followed in 2012

Following those organic examples, another 23 hashtags were developed with the following criteria:

- disease-specific
- short, unique, or minimally used on Twitter
- ending in “sm” for “social media” (as a prompt that online use is public)

<table>
<thead>
<tr>
<th>Hashtag</th>
<th>Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>#adcsrm</td>
<td>Adrenal cancer</td>
</tr>
<tr>
<td>#ancsm</td>
<td>Anal cancer</td>
</tr>
<tr>
<td>#ayacsrm</td>
<td>Adolescent and young adult cancer</td>
</tr>
<tr>
<td>#bcsm</td>
<td>Breast cancer</td>
</tr>
<tr>
<td>#blcsrm</td>
<td>Bladder cancer</td>
</tr>
<tr>
<td>#btsm</td>
<td>Brain tumors</td>
</tr>
<tr>
<td>#ccsrm</td>
<td>Colorectal cancer</td>
</tr>
<tr>
<td>#esocsrm</td>
<td>Esophageal cancer</td>
</tr>
<tr>
<td>#gyncsm</td>
<td>Gynecologic cancer</td>
</tr>
<tr>
<td>#hncsm</td>
<td>Head and neck cancer</td>
</tr>
<tr>
<td>#hpbcsm</td>
<td>Hepatobiliary cancer</td>
</tr>
<tr>
<td>#kscm</td>
<td>Kidney cancer</td>
</tr>
<tr>
<td>#lcsm</td>
<td>Lung cancer</td>
</tr>
<tr>
<td>#lnsm</td>
<td>Leukemia</td>
</tr>
<tr>
<td>#lymsm</td>
<td>Lymphoma</td>
</tr>
<tr>
<td>#melsm</td>
<td>Melanoma</td>
</tr>
<tr>
<td>#mmsm</td>
<td>Multiple myeloma</td>
</tr>
<tr>
<td>#pncsm</td>
<td>Pancreatic cancer</td>
</tr>
<tr>
<td>#pcsrm</td>
<td>Prostate cancer</td>
</tr>
<tr>
<td>#pedcsrm</td>
<td>Pediatric cancer</td>
</tr>
<tr>
<td>#scsmsm</td>
<td>Sarcoma</td>
</tr>
<tr>
<td>#scsm</td>
<td>Stomach cancer</td>
</tr>
<tr>
<td>#thmsm</td>
<td>Thymoma &amp; thymic carcinoma</td>
</tr>
<tr>
<td>#thysm</td>
<td>Thyroid cancer</td>
</tr>
<tr>
<td>#tscsm</td>
<td>Testicular cancer</td>
</tr>
</tbody>
</table>


HASHTAG UPTAKE

Organizing Online Health Content: Developing Hashtag Collections for Healthier Internet-Based People and Communities.
CROWDSOURCING THIS TALK!

To my fellow patients, what are your go-to digital resources for health information?

Asking to prepare a @SWOG talk on how we can curate online resources for maximum reliability and better engage those under our care & considering clinical trials.

Thanks in advance! #swogonc

Alicia C. Staley
@stales
Replying to @marklewismd and @SWOG
twitter is the search engine i use to surface the most timely resources. Look for ways to curate and uncover right info at the right time. impossible to curate a list of static sources. it’s about methodologies to FIND info

Enlightening Results
@GraceCordovano
Replying to @marklewismd and @SWOG
👉 UptoDate
👉 NCCN patient guidelines
👉 @twitter hashtags: disease specific, keyword, tweetchats
👉 healthcarebluebook.com/ui/consumerfro...
👉 @GoodRx
👉 @NationalPOLST
👉 @CoalitionCCC for #PalliativeCare & #EoL Resources
👉 @savvy_coop for gigs for patients to share their expertise 🧪
HOW OUR PATIENTS ENGAGE DIGITALLY

• 97% use the Internet to search for information about cancer

• 94% search on Google

• Results yielded:
  • Most accurate about etiology (70%) and symptoms (67%)
  • Least accurate about prevention (55%), treatment (55%), and prognosis (43%)
  • Tradeoffs between readability and reliability
  • Patients with rarer cancers are particularly vulnerable to the surfacing of misinformation
  • Searching about specific medications leads to pharmaceutical websites ~20% of the time


• Launched September 1998

• By August 1999, one billion searches per year were performed via Google

• By 2000, more than half of Google users had searched for health information at least once

• As of 2019, more than two trillion annual searches were performed, of which 7% were health-related, amounting to ~70,000 such queries per minute

• Health-related searches double in the weeks before a patient’s ER visit, and ~50% of patients who use Google in the week prior to presentation search for content directly related to their chief complaint

SEARCH ENGINE OPTIMIZATION?
PATIENTS VS. PAYWALLS

A pastor with stage IV leiomyosarcoma

Rev. Dr. Stacey Simpson Duke @revdrduke · Sep 6
Replying to @marklewismd and @SWOG
1: PubMed
2: search of the footnotes of the articles I find via PubMed
(if/when I hit a paywall, I ask any friend in medicine or academics to access it for me)

Ashley Farley @ashleydfarley · Sep 6
Replying to @mrgunn @dgmacarthur
People shouldn’t have to jump through additional hoops to access information because they aren’t privileged enough to be associated with an institution that can (nowadays its barely) afford subscriptions.

mrgunn @mrgunn · Sep 6
Yes, everyone should have rainbows, unicorns, & puppies delivered to their doorstep by volunteers. Y’all keep wishing for that, I’ll keep working on producing the best knowledge and distributing it as best we can.

Associate Officer of Knowledge & Research Services at the Bill & Melinda Gates Foundation

Elsevier’s director of scholarly communications

Deconstructing Cancer Patient Information Seeking in a Consumer Health Library Toward Developing a Virtual Information Consult for Cancer Patients and Their Caregivers: A Qualitative, Instrumental Case Study.
A NON-BINARY APPROACH

Top 100 Altmetric ratings in 2018 included:

#8 – complementary medicine, refusal of conventional cancer therapy, and survival among patients with curable cancers [JAMA Oncology]

#16 – death or debt? National estimates of financial toxicity in persons with newly-diagnosed cancer [American Journal of Medicine]

#22 – detection and localization of surgically resectable cancers with a multi-analyte blood test [Science]

#25 – association of frequency of organic food consumption with cancer risk [JAMA Internal Medicine]

#45 – adjuvant chemotherapy guided by a 21-gene expression assay in breast cancer [NEJM, ASCO plenary]

https://www.altmetric.com/top100/2018/
Of public posts, 7.5% are health-related

- In a study linking ER visits to social media posts, patients with a given diagnosis in the EMR were significantly more likely (p<.0008) to use terms related to that condition on Facebook
- Patients self-disclose signals about their mental & physical health

<1% of posts concern clinical trials and research studies


"DESTINY SHARING" IN GROUPS

For Health Communities, Facebook is Too Important to Delete
Social Media and SWOG:
Using it to enhance clinical trial development, conduct, and dissemination

Michael J. Fisch, MD MPH
The University of Texas MD Anderson Cancer Center

SWOG Plenary: May 4, 2013
THE SHIFTING PROPORTION OF “VOICES” ON TWITTER AROUND ASCO ANNUAL MEETINGS
WE CANNOT TAKE OUR ADVOCATES FOR GRANTED

Alicia C. Staley
@stales

Replying to @corrie_painter @symplur and 10 others
i’ve been seeing/sensing (but haven’t proven via numbers...yet) a very cyclical nature for advocacy via social – when some advocates pass away (@jodyms, @whymommy, @ccchronicles, @regrounding, @AdamsLisa, @JackWhelan, @CultPerfectMoms xoxo) void takes time to fill #bcsm #asco19

5:44 PM · Jun 7, 2019 · Twitter for iPhone
A QUARTER-CENTURY OF PROGRESS
THIS IS WATER