

Finding & Evaluating Online Medical & Support Information

Karl Schwartz, BA, MFA

Caregiver, Patient Advocate | Patient Consultant to FDA, ODAC

President, Patients Against Lymphoma

www.lymphomation.org

The views expressed are the results of independent work and do not necessarily represent the views of organizations to which the author is associated.

TOPICS

- ✓ **Support**
- ✓ **Trust**
- ✓ **Evidence-based decision-making**
- ✓ **Strategic Searching**



SUPPORT

The compounding impacts of
cancer and cancer treatments

on patients and families

Physical | Psychological | Social

The Whole Patient

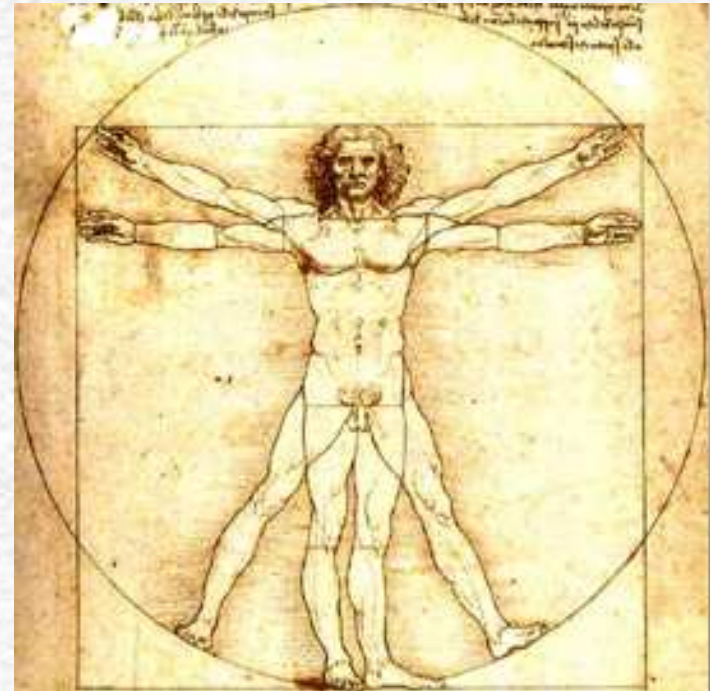
Impacts of cancer/treatment on patients and families

Physical & Psychosocial

- **Physical**
- **Psychological**
- **Financial**

Impacting:

- **Decision-making**
- **Access**
- **Quality of life**



**Cancer Care for the Whole Patient:
Meeting Psychosocial Health Needs (2008)**

http://books.nap.edu/openbook.php?record_id=11993&page=1

"losing control"

Jackie writes:

"I was a **complete mess** when I found out I had Lymphoma.

Then I started dealing with it; trying not to **think about it all the time.**

Some **family members** don't even know @ the most maybe 10 are aware I have this cancer.

I might have went about it the wrong way,
I feel like I am **losing control now.**"



Variables

- ✓ Cancer type (risk and natural history)
- ✓ Treatment type (short and long term effects)
- ✓ Patient status
age*, temperament, skills, health, beliefs,
family and social network ...
- ✓ Status of local Health Care system

* “**older adults** with cancer are more likely to present with a preexisting chronic disease and increased functional impairment and disability, which can compound the stresses imposed by cancer” (Hewitt et al., 2003).

Challenges

👉 **Outreach** ability to ask for and find help

👉 **Navigation** of highly complex / fragmented health system

👉 **Communications** with care providers / insurers

👉 **Coordination** among different specialties, nurses, ...



👉 **Financial** insurance | billing | ability to work ...

👉 **Education** informed partner in medical decision-making

Physical Impacts

Health Impairments

- Disabilities chronic illness, sexual, fertility
- Fatigue and pain
- Cognitive impairment

Compounding psychosocial impacts

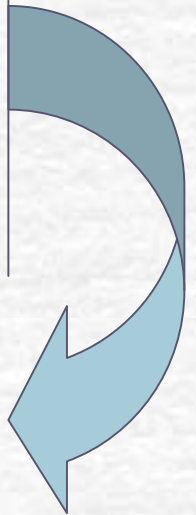


“Survivors of **childhood cancer** similarly have much higher than average rates of chronic illness beginning in their early or middle adult years.” (Ness et al., 2005).

Financial Impacts

- ☛ Career / Job / Dependents / Home / Food
- ☛ Follow up / Compliance / Supportive care
- ☛ Purchase medications / supplies
- ☛ Insurance (am I covered)?
- ☛ Travel to treatment
- ☛ Access to second opinions (best care)?

Compounding psychological impacts ...



Psychological Impacts

- Depression
 - Fatigue and lower functioning
 - Impacts on social relationships / career
- Poor decision making
- Denial
- Vulnerability to Fraud
- Impaired ability to ask for help

Post-traumatic stress outcomes in non-Hodgkin's lymphoma survivors

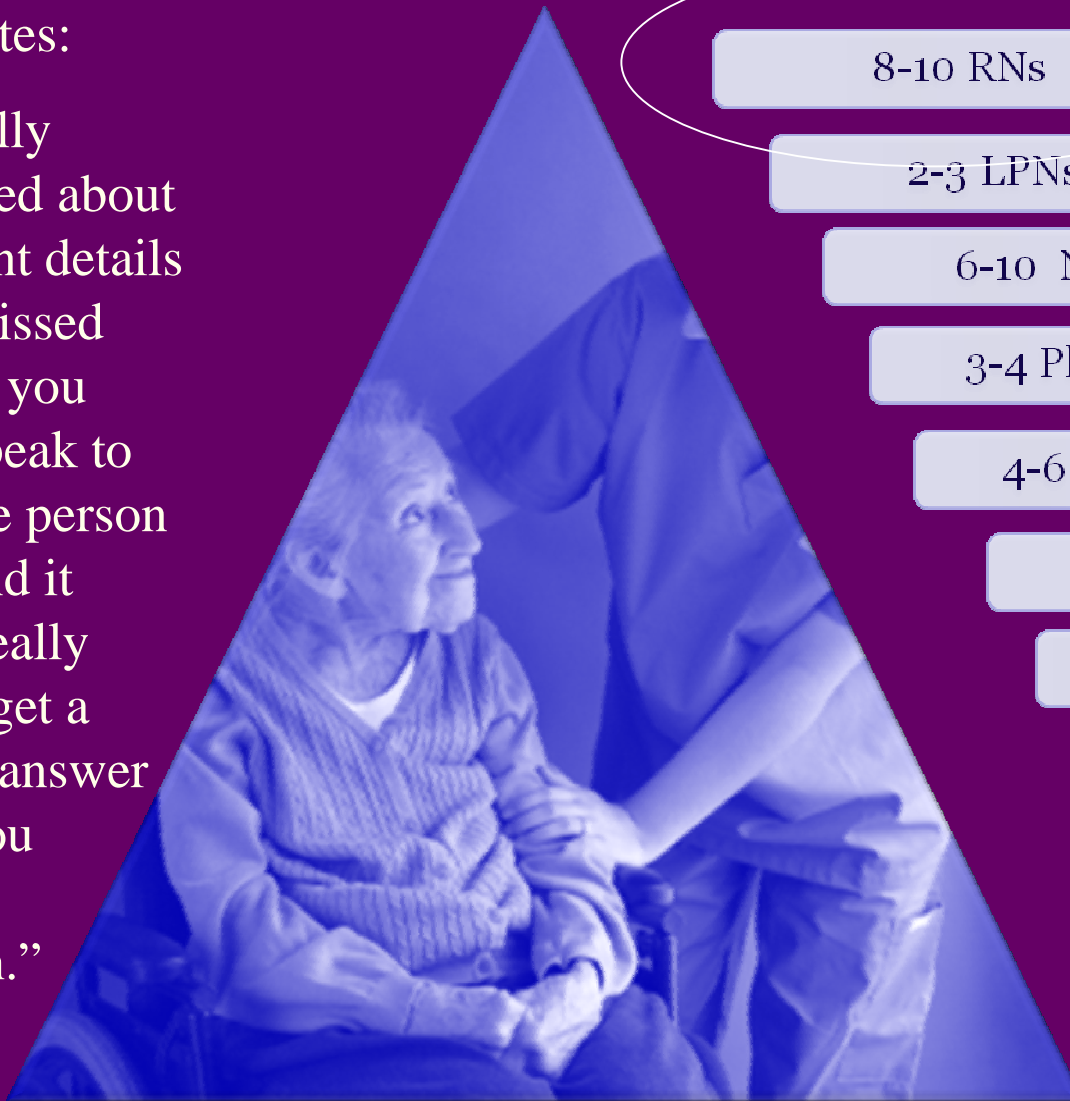
(Smith SK, Zimmerman S, Williams CS)

<http://www.ncbi.nlm.nih.gov/pubmed/18281667>

Patient and Family Reality

Deb writes:

“I'm really concerned about important details being missed because you never speak to the same person twice and it seems really hard to get a straight answer when you ask a question.”



8-10 RNs

2-3 LPNs

6-10 NAs

3-4 Physicians

4-6 Residents

1-2 Physical Therapists

2-3 Imaging Techs

1 Home Health RN

4-5 Dietary/Food Service

4-5 Housekeepers

2-3 Transporters

Slide courtesy of
Creative HealthCare
Management

Patient's Story: Lost in the Shuffle?

Bring List

Bring to all consults:

- ✓ Trusted friend or relative
- ✓ Referral (primary care doc)
- ✓ Insurance cards
- ✓ Authorization (insurance)
- ✓ Contacts: emergency, other docs, local pharmacy
- ✓ Diagnosis, treatment and medical history (concise)
- ✓ Medications, supplements, allergies list
- ✓ Symptoms / side effects list

Written questions (such as):

- ✓ All appropriate options?
- ✓ Rationale for recommendation
- ✓ Second opinion? | Clinical trials?


First visit / second opinion:

- ✓ Pathology report & slides
- ✓ Radiology reports / film

Ask about:

- ✓ Care managers
- ✓ Mental health professionals
- ✓ Pain specialists
- ✓ Physical therapists
- ✓ Nutritional experts
- ✓ Social workers / financial help
- ✓ Support groups
- ✓ Copy of test results
- ✓ Next consult / test / treatment?


Support Resources (example)



Ask Question
Sign Guest book


Lymphoma**lion**.org

[About Lymphoma](#) | [Advocacy & Art](#) | [CAM & Life Style](#) | [Clinical trials](#) | [Docs & Centers](#) |
[Guidelines at Diagnosis](#) | [How to Help](#) | [Side Effects](#) | [Support](#) | [Symptoms](#) | [Tests](#) |
[Treatments](#) | [Types of Lymphoma](#)



Experts

Support

Support & Survivorship

Last update: 07/11/2009

TOPICS

[Alerts / Keeping Safe](#) | [Psychosocial](#) | [Doctors](#) | [Financial & Insurance](#) | [Drugs](#) | [Immunization Guide](#) |
[Treatment Support & Tips](#) | [Patient-to-Patient \(right column\)](#)

NEW


- Long-Term and Late Effects of Treatment in Adults [leukemia-lymphoma.org](#) pdf
- Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs [books.nap.edu](#)

Alerts and Keeping Safe

- [Consumer Guide on Counterfeit Drugs](#)
how to avoid and report the sale of bad medicines
- [Keeping Safe](#) - how to minimize your risk from medical errors
- [Health Supplement Alerts](#)


Psychosocial: Emotional / Quality of Life

- [Anxiety and Depression](#)
- [Books that provide guidance](#)
- [Caregiver Stress & Caregiver Tips](#)



[Patient-to-Patient Support](#) | [Patient Stories](#)

[Art](#)
Images and poems created by patients and caregivers that portray the experience of living with lymphoma.



[Books](#)
Patient-recommended books on living with lymphoma and its treatment

[Caregiver Stress](#)
Help with identifying and relieving caregiver stress.

[Caregiver Tips](#)

["Buddies" Programs](#) - peer-to-peer support with guidance on [How to Help a Friend](#)

Support Resources

examples

- Government

www.cancer.gov | www.cms.hhs.gov

- Non-profit

www.cancer.org | www.LLS.org

- Professional groups (physicians, other)

www.cancer.net

- Peer-to-peer (non-profit - patient/caregiver)

Look for online support forums sponsored/monitored by non-profits or professional groups, although many excellent ad hoc groups exist.

Online Peer-to-Peer Support Groups

consistent moderation & guidelines



Benefits	Caveats
Community: I'm not alone	Privacy risks
Pooled experience	Uneven quality: Error / fraud?
24/7	Personality or ideological conflicts
Give, Ask, Participate, "Lurk"	Computer skills / typing?
News, Clinical trials ...	Too much information
Good when evidence-based	Anecdotal? Testimonials?

Participation is an very good way for health care providers
to learn about and meet support needs.



TRUST

Benefits and Risks of Consulting Online Medical Resources

Red Flags:
Signals of implausible
& fraudulent Information

Seeds of Mistrust

falsehoods and misinformation in books/online

Falsehoods directed to vulnerable:

- *"Practicing physicians are intimidated into using regimes which they know do not work"*
- *"Everyone should know that the the 'war on cancer' is largely a fraud' wrote Dr. Linus Pauling."*



“OPTIONS: The
Alternative Cancer
Therapy Book”

Sites/books may falsify risks of standard medicine, then promote “no-risk” Alternative therapies (diet, herbs, etc.)

Experts and Authors?

- ☛ **Danger:** persuasive non-experts, media personalities, giving opinion as facts.
- ☛ **Caution:** there's the motherly affection for one's idea ... the expected blindness for its imperfections. **Author-bias.**
- ☛ **Eminence / personality is not evidence**
- ☛ Expert credentials add credibility/plausibility, ... but, human and disease biology is too complex to predict results without clinical testing.

Bias, Error, and Theft?

BIAS	ERROR/CHANCE	THEFT
Prejudging?	Poor study design	Intentional,
Wishful thinking?	Small single-arm study	Misleading for profit,
Author/sponsor interpretations?	Subset analysis (low power)	Taking advantage of vulnerable
Conflict of interest?	Not reproduced by independent group	Outright fraud is rare in the peer system / common for Alt Med
Sponsor media releases		

In a study design, a bias is defined as an error in the method of study that leads to a deviation in the outcome away from the truth.

Red Flags

- ❖ **Conspiracy**
- ❖ **Testimonials**
- ❖ **Treats ALL cancers**
- ❖ **Promoted by ONE practitioner?**
non-doctor, layperson, or doctor working outside field
- ❖ **Promotional language**
- ❖ **No side effects –**
- ❖ **Natural** using preclinical science to support
- ❖ **No references to published clinical studies**



“Good intentions may do as much harm as malevolence if they lack understanding.” ~ Camus

Testimonials?

Verification?

- Truthful? | How benefit was measured?
- Follow up? How long effects lasted?



Clinical details?

- Prior / subsequent standard treatments disclosed?
- Natural history of the disease?

N = 1 ... no denominator (not evidence)

- How many did not benefit / were harmed?
- Can't predict benefit / risk in others

Conspiracy?

Scientists, doctors,
regulators, nurses ...
and their loved ones
get cancers



Would require the silent complicity of
experts, parents, worldwide ...
when they themselves
or their loved-ones are diagnosed



Detail: www.lymphomation.org/BigPharma.htm

Alternative Therapy for Cancer?

- 83 million Americans used it (cancer / other)
- \$32.7 billion dollars (1997)
- 425 million Alternative therapy visits, compared with 388 million visits to primary care providers
- 70% to 90% will not mention Alternative therapy visits to their physicians

Journal of Clinical Oncology, Caring (Really) for Patients
Who Use Alternative Therapies for Cancer

<http://jco.ascopubs.org/cgi/content/full/19/23/4346>

Signal? inadequacies of our health care system



The skeptic's case: www.lymphomation.org/wwlife.htm

Reputable?

- Is it **up to date**?
- Is **author** identified and credentialed?
- Do **several sources** report similar information on topic?
... or just one?
- Are **source studies** cited?
- Is it **biased** favoring product / service they sell?
- Are conclusions based on **case report / testimonial**?

- Reputable physicians** do not diagnose, recommend or treat patients online without physical exam.
- Be cautious if asked for **personal health information**.
- Opinions** or **testimonials** should be clearly labeled so as **not** to be confused with **fact**.

**"If it's too good to be true,
 it probably is"**

Adapted from: Using the Internet for Reliable Health Information,
March 17, 2009, Amber J. Tresca, About.com

Evidence-based decision-making

Key Questions | Goal of Therapy
Levels of Evidence

Benefits / Risks of consulting online resources

Benefits	Risks
Empowering	Difficult / complex material
Could save your life (clinical trial, new approved therapy)	Misinterpretation / lacking broader perspective (gaps in knowledge)
Fosters shared decision-making	Facing / understanding statistics
Can reduce risk of medical error, contribute to informed consent	Not recognizing erroneous / low-level / fraudulent information

"Remember that all of our reading is a way of having more productive conversations with our medical providers. So, we can always get them to help us through these judgments too." ~ *Andy M. (advisor)*

Key Questions



- Can it work for me?
- How likely will it work
 - for me
 - in my cancer
 - in my setting (age, stage)
- Is it worth it?
 - Benefits outweigh risks?
- Does it have advantages over available therapies?



Seeking evidence-based
information for decision making

Standards of care?
Off-protocol?
Investigational?

Goal of Therapy

Varies widely by cancer type and clinical circumstances

Cure? | Watch & Wait? | Manage as chronic condition?
Improve Quality of Life?

Depends on

- ☞ Type of cancer (high/low-risk) ... natural history
- ☞ Widespread / Localized / Where?
- ☞ Efficacy of tested protocols (see statistics next page)
- ☞ First treatment or Relapsed
- ☞ With which approach will I live longer or better (evidence)?
 - Aggressively? Watch and wait? Minimally as needed?

Acceptable risks / side effects:

- ☞ Higher for high-risk cancers (vice versa)

Survival Statistics

not to predict individual outcomes (prognosis)

☛ Frightening to patients/caregivers

Limitations

- Median is a middle point in a range of outcomes
- General, calculated on large groups
- Includes death from any cause
- Skewed by age of population
- Does not account for
 - Recent advances | Individual circumstances



The Median isn't the Message, by Jay Goulde

http://cancerguide.org/median_not_msg.html

Levels of Evidence

Level	Study Type	
Proven	Phase III randomized	Evidence of clinical benefit Reproducible results!
Promising	Phase II single arm	Signals of efficacy dose refinements (dozens)
Plausible	Phase I – dose finding	Dose finding Is it safe at active dose? (hundreds)
Starting point	Preclinical animal or cell culture	Activity? (1 in 5,000) Long shot – most are toxic at active doses
Theory	Good science or pseudoscience?	(Infinite)



On pseudoscience: <http://en.wikipedia.org/wiki/Pseudoscience>

Types of Studies

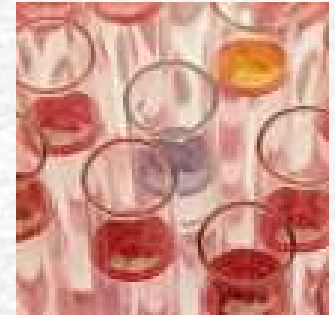
focus on clinical

☛ **Cell culture** only 1 in 5,000
win marketing approval *

☛ **Animal studies** - starting point
rarely predictive of benefit in humans

☛ **Human** (Clinical) only phase III
provide evidence of clinical benefit

Preclinical



Take home point: look for hope in
clinical-phase studies





STRATEGIC Searching

locating evidence-based resources

Abstracts

a condensed version of published study findings

- ☛ Caveats: Not all that's published is gold
 - The *rush* to publish
 - Lacks detail: methods, side effects
 - Promotional conclusions?
- ☛ At a glance: (relevant to me? / level of evidence?)
 - Study population? | Big / small? (n) | Clinical or Preclinical?
 - Old/new? | Other groups studying? | Where published?
 - Randomized or single arm?
 - Review article? Systematic is best
- ☛ Start with PubMed: index of abstracts ...



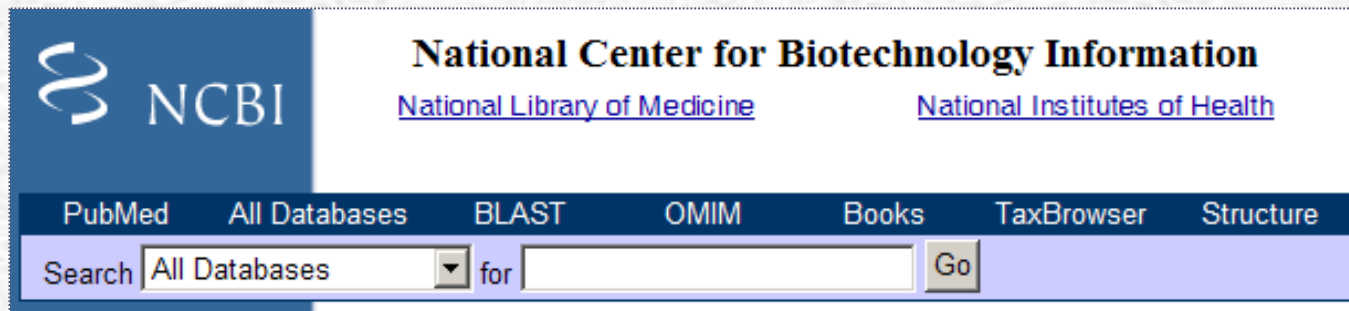
Good start: Provides also links to related articles and full text

PubMed

start here to search abstracts

Published results ONLY

- not commercial sites, press releases, junk science

A screenshot of the NCBI PubMed search interface. The top section features the NCBI logo on the left and the text "National Center for Biotechnology Information" in bold, with "National Library of Medicine" and "National Institutes of Health" as links below it. A navigation bar contains links to PubMed, All Databases, BLAST, OMIM, Books, TaxBrowser, and Structure. Below this is a search bar with the text "Search All Databases" and a dropdown menu, followed by a "for" label, an empty search input field, and a "Go" button.

NCBI

National Center for Biotechnology Information
[National Library of Medicine](#) [National Institutes of Health](#)

PubMed All Databases BLAST OMIM Books TaxBrowser Structure

Search All Databases for Go

includes over 18 million citations from MEDLINE
and other life science journals back to 1948

www.ncbi.nlm.nih.gov

link to full text article and related articles

Treatment Resources

Standard of Care

- www.Cancer.gov | www.NCCN.org

Clinical Trials - Investigational

- www.ClinicalTrials.gov
where the preclinical work has already been done
- then search PubMed or ASCO.org:
www.ncbi.nlm.nih.gov/ | www.ASCO.org

Key words: Safety, efficacy, mechanism of action

Other

- ASH.org (blood) | Medscape.com | PubMed

Strategic Filtering (investigational)

Investigational treatment if needed:

- **START** with: www.Clinicaltrials.gov then search:
- **PubMed** to avoid commercials / ads / media
www.ncbi.nlm.nih.gov
- **Google site search** by typing:
site:www.asco.org lymphoma
site:www.cancer.gov "drug name"

Use dictionaries as needed:

- NCI: www.cancer.gov/drugdictionary

Strategic Filtering (support)

Go	Caution
Gov Edu Org Typically more reliable domains	COM commercial Press releases (sponsor)
Non-profits: ACS, LLS other accredited cancer-specific orgs	Phishing? (looks real but isn't)
Peer support (sponsored by credible orgs)	Promotional / ads
Open-source Wikipedia (+)	No references / Red Flags?
Search	Specific Sites
Sites with Google	site:www.cancer.org <i>keyword</i>
PubMed index	http://www.ncbi.nlm.nih.gov/

In Summary

- the Whole Patient: there are many urgent needs
- Trust? Understanding of scientific method and standards for evidence is lacking in the general public
- Hope, not Hype:
 - Best practice: based on type and stage of cancer, goal of therapy, standard of care / investigational ...
 - Red flags: conspiracy, ALL cancers, testimonials
- Strategic Searching: Where and how to look

Thanks for listening!

A horizontal band of light blue wavy lines, resembling stylized water or clouds, spanning the width of the slide.

APPENDIX

Supplemental slides
& narrative
will be available:

www.Lymphomation.org/online-support.pdf