

Finding & Evaluating Online Medical & Support Information

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

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Welcome and thanks for joining in.

I'm Karl Schwartz, president and cofounder of Patients Against Lymphoma

As shown, I'm a caregiver, and patient advocate and have developed the content of our website, lymphomation.org. I must credit the online patient community for the direction of my continuing education, but also many professional advisors and the education provided by teachers at FDA as well.

Please note that this talk is based on independent work, and does not represent the views of organizations I am associated with, including the exceptional sponsor of this event, the Leukemia & Lymphoma Society.

TOPICS

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

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Slide 2 provides an outline of what we'll cover.

Each topic could be the basis of a single presentation. My hope is that I can tie them together in useful ways. So that you will be able to better use online medical and support resources, or, more importantly perhaps, help the individuals we serve to do the same.



Slide 3 begins the support section, with a focus on the compounding impacts of cancer and cancer treatments on patients ... and families.

The Whole Patient

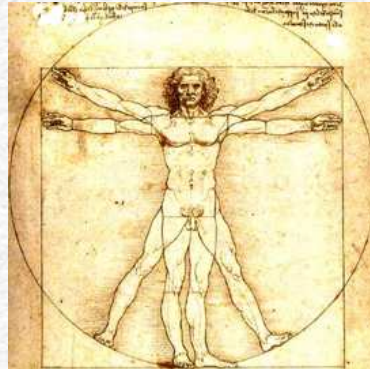
Impacts of cancer/treatment on patients and families

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

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We know that achieving health is not limited to treating biological processes ... that the impacts of the disease and the toxicities of treatment can have profound physical, psychological and social impacts, which can impair decision-making, diminish your quality of life ... or the ability to provide for your family.

Treating the **WHOLE** patient is a challenging ideal that is rarely met by our present medical systems.

Cancer Care for the Whole Patient – is an excellent, and well-referenced resource on this subject. See link provided.

"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.**"



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I think Jackie's words speak to the emotional stress of a cancer diagnosis ... the sense of isolation, ... and loss of control over one's life.

In the Perfect Storm, the narrator describes DANGER as a narrowing range of choices.

With the diagnosis of a cancer, there is no escaping danger and risk, we can only exchange one kind for another –

The risk of the disease untreated, versus the toxicities and uncertainties of therapy.

There are two aspects of therapy that are well-known to cancer patients.

.. that you might not benefit ... that is, that you may experience mainly unproductive toxicities,

And that these effects can narrow the range of future treatment options.

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).

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Slide 6 shows some of the variables that can affect the types of support that cancer survivors may need.

As we know, each patient, cancer, and treatment can be unique and that impacts will vary accordingly.

The patient’s status -- such as her age, preexisting conditions, availability of social networks -- may also help determine the types and amount of needed support.

Perhaps a checklist for such factors will assist health care providers - helping to identify at-risk patients and families?

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



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Turning to Challenges on slide 7:

As we know, there are many. The medical delivery and insurance systems are very complicated.

So there's a need to help patients to navigate it – especially persons who will be unable to ask for and find support. For example, those who are depressed, or do not have access, or skills, to utilize online support networks.

Educational materials are needed to help these patients and caregivers to become informed participants, better able to communicate effectively with the many providers – across different specialties.

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).

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Moving on to Slide 8:

The physical impacts of cancer and cancer treatment, such as chronic pain and fatigue are not easy to recognize or measure.

Methods or procedures are needed to help patients communicate these effects objectively and easily so that they can be addressed and mitigated.

By doing so, we can help to reduce the pain and suffering associated with cancer and cancer treatments.

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 ...

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On slide 9 we show some of the better-known financial stresses experienced by cancer survivors and their families.

As you know, providing financial support and guidance will also help to relieve the psychological burden of cancer.

Our sense, based on online questions, is that many patients and families are not be able to manage these issues effectively without help.

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>

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Slide 10 shows some of the many psychological effects of cancer and cancer treatment.

Notably, among participants in the Post-traumatic stress study cited here, 17% experienced full to partial PTSD symptoms – illustrating that the emotional impacts of cancer and treatments can be severe.

Again, these effects can cause physical symptoms and can also impair your ability to work, to relate to others, or to make rational medical decisions.

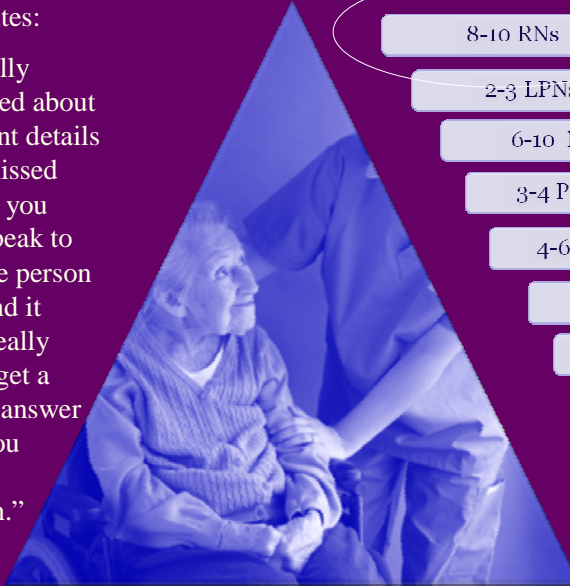
==

the adjusted prevalence for full PTSD was 7.9%, with an additional 9.1% meeting criteria for partial PTSD.

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?

Slide 11, was provided courtesy of Creative HealthCare Management

Within a hospital setting, for example, the opportunities for error are magnified by the growing complexity of modern medicine, but also as responsibility for the administration of treatment is handed one to another, and no single person has responsibility or oversight.

Please note Deborah's comments, which validates this groups conclusion that a Relationship-based System may be required – that assigns one professional to coordinate care and follow up .. from admission to discharge and beyond.

Bring List

<p>Bring to all consults:</p> <ul style="list-style-type: none"> ☞ 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 <p>Written questions (such as):</p> <ul style="list-style-type: none"> ☞ All appropriate options? ☞ Rationale for recommendation ☞ Second opinion? Clinical trials? 	<p>First visit / second opinion:</p> <ul style="list-style-type: none"> ☞ Pathology report & slides ☞ Radiology reports / film <p>Ask about:</p> <ul style="list-style-type: none"> ☞ 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?
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www.lymphomation.org/bringlist.pdf

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Moving to the next item in this section, slide 12:

Prepared patients and caregivers can do a lot to optimize medical health care delivery.

For example, our group provides the following Bring List to help patients organize materials and key questions .. for the purpose of optimizing medical consults:

A trusted friend or relative

A referral

Various lists

Your diagnosis and medical history ...

Written questions to ask, and so on.

Support Resources (example)

The screenshot displays the Lymphomation.org website. At the top, the site's name is in a purple font. Below it is a navigation bar with links: Ask Question, Sign Guest book, About Lymphoma, Advocacy & Art, CAM & Life Style, Clinical Trials, Docs & Centers, Guidelines at Diagnosis, How to Help, Side Effects, Support, Symptoms, Tests, Treatments, and Types of Lymphoma. A blue banner reads "Support". Below this is a green box titled "Support & Survivorship" with a butterfly icon and the text "Last update: 07/11/2009". A "TOPICS" section lists: Alerts / Keeping Safe, Psychosocial, Doctors, Financial & Insurance, Drugs, Immunization Guide, Treatment Support & Tips, and Patient-to-Patient (right column). The page is divided into two columns. The left column, under a "NEW" heading, lists: Long-Term and Late Effects of Treatment in Adults (link to leukemia-lymphoma.org), Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs (link to books.nap.edu), Alerts and Keeping Safe (with sub-links for Consumer Guide on Counterfeit Drugs, Keeping Safe, and Health Supplement Alerts), and Psychosocial: Emotional / Quality of Life (with sub-links for Anxiety and Depression, Books that provide guidance, and Caregiver Stress & Caregiver Tips). A blue arrow points down from the last link. The right column, under "Patient-to-Patient Support | Patient Stories", includes: Art (with a yellow flower icon and text about images and poems), Books (patient-recommended books), Caregiver Stress (help with identifying and relieving stress), Caregiver Tips, and "Buddies" Programs (peer-to-peer support with guidance on How to Help a Friend).

Lymphomation.org

Ask Question | Sign Guest book | 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](#)

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Slide 13, shows the Survivorship topics that we provide on our website – lymphomation.org. The content, determined by patient and caregiver questions.

Many of these topics are not specific to lymphomas, and each page provides links to government, education, and nonprofit resources.

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.

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On Slide 14 we see examples -- sources for reliable support information -- provided by

Government, Non-profits, and Professionals groups,

... such as

Cancer dot ORG,
dot NET

and dot GOV (Three easy sites to remember)

Peer-based support groups are also available on the Internet, and are very active.

More on the helpful and risky aspects of peer-to-peer support groups will follow on slide 15.

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.

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Online groups can provide a vital lifeline for patients ... a community of understanding peers with a wealth of experiences to share. The good features listed in the Benefits column, such access any day or time of day.

But there are caveats, such as privacy risks, and occasional personality conflicts.

Optimal participation also requires some computer and typing skills.

You can get TOO much information, and some groups may be targeted by individuals or commercial entities promoting products, books, or strongly-held personal beliefs.

However, these risks can be managed with clear guidelines and consistent moderation.

Key point: Remind everyone that online correspondence is like public speaking (emails can be wrongly forwarded or intercepted sometimes). Choose your words and sentiments accordingly!



So how do you know what can be trusted when consulting online resources?

This section, starting on slide 16, is about that.

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.)

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The disturbing quotes on Slide 17 were captured from Options: The Alternative Cancer Therapy Book.

A well-meaning neighbor gave me a copy when my spouse was first diagnosed. I can tell you that the layperson will often find these perspectives compelling.

The formula in this case is to plant seeds of mistrust: falsify the risks and motives for standard cancer therapies, and then to offer unproven practices as acceptable alternatives.

As we know, standard therapies have been evaluated in comparative clinical studies and must have at least the potential to improve survival or quality of life, relative to the disease untreated or treated differently. As we know, there are a good number and types of cancers that can be cured or manage well.

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.

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It important for all of us to recognize our limitations and to give opinions cautiously, particularly outside of our fields.

If an author has persuasive skills and a wide audience, the potential to do harm is great, even if the intent is good. History has many sad examples.

Even among experts there are boundaries about opinion, and typically the higher the skills the better able the experts are to distinguish between what they know (based on reproducible experiments) and what is yet to be proven or demonstrated.

Fortunately, in our drug review system, we do not rely on “mother's” opinion! Being an expert adds credibility to what is said, but only by the rigorous testing of a theory can we trust it ... can it rise to the level of evidence.

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.

19

Slide 19 shows the many reasons to be skeptical about conclusions and promotions, no matter the source, grouped here by Bias, Error, and Theft.

"While we may think conflicts of interest involve overt corruption, ... research suggests that bias is more frequently the result of motivational processes that are unintentional and unconscious "

Regarding the need for objective tests, Gregory L. Smith writes, in his essay 'Common Questions about Science and "Alternative" Health Methods'

"Scientists realize how easy it is to be deceived or to fool ourselves even without knowing it, especially when we dearly want something to be true. That's why science always tests remedies in a way that could show that they were ineffective. We should all be open to the fact that we could be wrong, and design our tests accordingly."

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

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On slide 20 we have listed some common red flags for implausible and fraudulent online information about cancer treatments. Probably these are obvious signals to health care professionals.

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

See also www.lymphomation.org/Testimonials.pdf

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Testimonials do not deserve our trust – and should instead be regarded with suspicion.

Many of the stories of “cancer cures” or “responses” cannot be verified as true, and do not inform us about how clinical benefit was defined or measured ... or how long it lasted? ... or if prior or subsequent standard therapies were responsible for the outcomes?

And individual outcomes, even when verified, cannot establish causality – that A caused B, nor can they help to predict outcomes for others – people hit the lottery, but that doesn't make playing the lottery a good bet, particularly when betting your life.

Further, spontaneous remissions can occur in cancers, for indolent lymphomas this is in fact quite common, and these events will be incorrectly associated with life style practices – what one happened to eat or take at the time.

Finally, as we know, people who die cannot provide testimonials.

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

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As touched on earlier, alternative sites will plant seeds of mistrust as a way to explain why their treatments are not practiced by licensed doctors.

**We read: “Big Pharma Conspiracy Keeps Cures from Patients”.
“Doctors Prescribe Chemo for Profit”**

But a conspiracy would require the silence and complicity of doctors, scientists, nurses and regulators who also get cancers, whose children also get cancers; it would require also the complicity of numerous drug companies who are developing and testing competing products.

So there’s a need to educate the public on this issue, so that patients mistrust the right sources: the unproven and typically implausible alternative treatments for cancer, sustained by testimonials.

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

23

On Slide 23 I've pulled some findings published in the Journal of Clinical Oncology – regarding the use of alternative medicine in the United States

By definition, “alternative medicine” means the use of unproven or untested practices to treat medical conditions.

(It should not be confused with complementary practices, such as yoga and meditation, which have very different and useful objectives.)

Remarkably, the report states that there have been 425 million Alt med visits, compared to 388 million visits to Primary Care Providers in the period studied.

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

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Turning to Slide 24, and what is reputable: A checklist.

It's reassuring when several sources say the same thing and the information is current. But mistrust is earned when no references are cited, or when conclusions favor the product or service they sell.

As noted earlier, opinions and testimonials should be labeled as such and not conveyed as evidence or facts.

Conclusions based on case reports should raise suspicion - whether found on websites or in published abstracts.

NOTE: The difference between a case report and a testimonial is that the former can be validated by a licensed physician. But the degree of trust is subject to the biases and special interests of the practitioner, even if a medical doctor. For example, does the finding validate an unorthodox service the doctor provides for a fee, or the research interest of an investigator? ... or is it an notable event observed during the course of a normal medical practice (by a disinterested party)?

Evidence-based decision-making

Key Questions | Goal of Therapy
Levels of Evidence

25

Think of this section, beginning on slide 25, as information you might convey to your patients to help them to make better sense of the medical literature and ask more informed questions of their doctors:

The goal being to be come active partners in medical decision-making.

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)*

Adapted from: www.cancerguide.org/pros_cons.html

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Slide 26 lists some of the risks and potential benefits of consulting online medical resources.

The patient who consults reputable resources can ask informed questions of his doctor – raising the level of care, and may protect himself from medical errors.


As in: "Can you check the prescription, ... are you sure it's the right drug or dose?"

Or "Doctor, might we also consider this clinical trial? ... does this data seem compelling to you?"


But when consulting medical journals the patient must also face mortality statistics, and distinguish between weak and strong medical findings.

I've copied Andy's comments on the purpose of such research: that it's to help us participate and have more productive conversations with our doctors, not to make medical decisions independently.

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?

27

Slide 27 provides key questions to ask of our doctors (and the research we consult) when considering medical interventions.

Can it work for me? How likely? ... What are the risks and potential benefits?

What clinical evidence support this use?

How does it compare with other reasonable options?

Is the recommended treatment the standard of care?

When do I consider a clinical trial?

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 / 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)

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For some cancers the standard of care is well-established . For other types the selection of first or second line therapy is controversial and the patient might be asked to decide from a “menu” of choices.

The goal of therapy can range from treating aggressively with curative intent to a management approach – treating minimally as needed. It’s dependent on the type of cancer and the risk associated with its expected clinical course, but also the efficacy data for available protocols for that indication.

For example, for the indolent lymphomas, patients and families are often surprised to learn that sometimes it’s just observed and monitored and that there’s no reason or benefit to early or aggressive interventions.

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

29

Slide 29 is about the difficulty patients will have when confronting survival statistics, which may be required in order to make informed treatment decisions.

Patients may confuse survival statistics with prognosis, thinking it predicts how long they have to live.

==

So educational materials are needed to help patients to understand the purpose of statistics:

that it's to establish trends and compare outcomes in large groups;

that it's not for the purpose of predicting individual outcomes.

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>

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To Slide 30 and the relationship between levels of evidence and study type.

The basis for trust in decision-making, in yellow, the gold standard is the controlled and reproducible clinical study that demonstrates clinical benefit – such as improved survival or quality of life.

Be aware the a good number of phase II studies that appear promising are not validated by controlled studies, which more objectively measure both risks and benefits.


But for some indications and clinical circumstances we may have to base medical decisions on less reliable clinical or preclinical reports.

Types of Studies

focus on clinical

- r **Cell culture** only 1 in 5,000
win marketing approval *
- r **Animal studies** - starting point
rarely predictive of benefit in humans
- r **Human (Clinical)** only phase III
provide evidence of clinical benefit

Preclinical



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

* Product Pipeline and Clinical Trials: Bringing a Drug to Market
<http://www.biology.iupui.edu/biocourses/Biol540/4pipeline2k5.htm>

The take home point for slide 31 is that the overwhelming majority of preclinical studies do not lead to medicines that provide clinical benefit – are found to be ineffective or are too toxic at therapeutic doses.

Unfortunately, we see non-standardized supplements promoted as helpful against cancers based on preclinical studies – with no information provided regarding the effective dose and toxicities at that dose – or if the active compound is merely excreted when taken orally. Also noteworthy is that cancer cells studied in preclinical models are not equivalent to malignant cells that originate in humans. Mice, for example, are cured routinely of cancers.



STRATEGIC Searching

locating evidence-based resources

32

In the final section, beginning on slide 32, we'll introduce a few basic tips to help us to more efficiently find reputable information about cancers on the Internet.

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](#)

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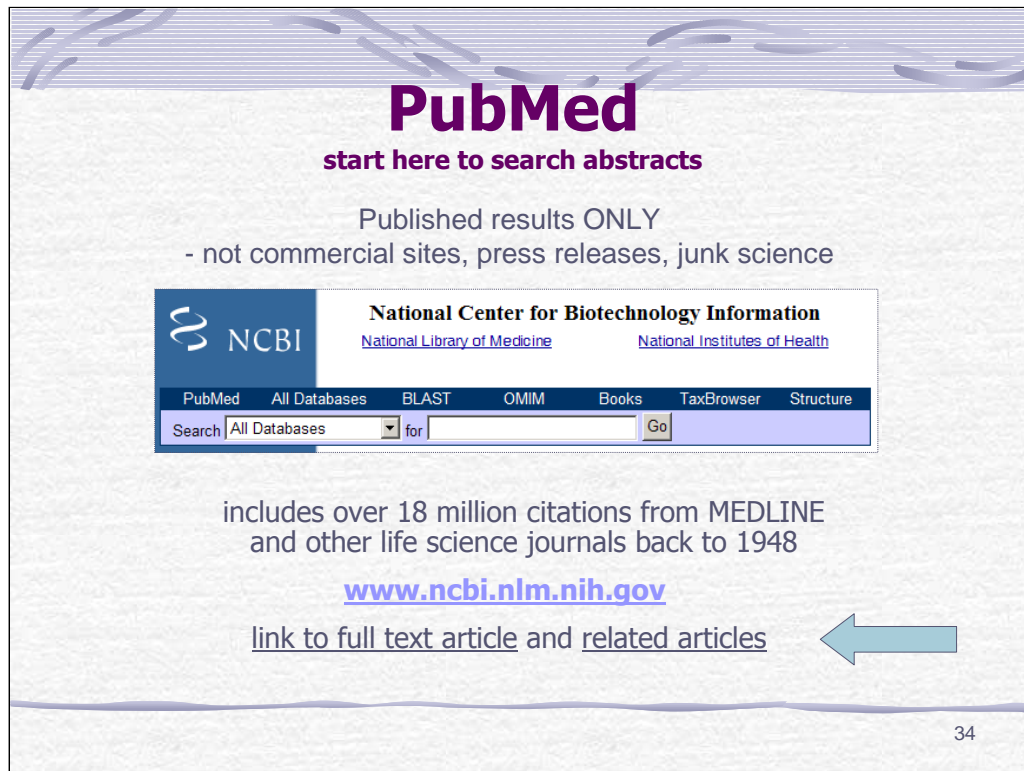
Slide 33 is about abstracts, which, as you know, are condensed versions of published studies.

Patients may not be aware that not all studies are well-done, or of a type that can support definitive findings on which to base medical decisions.

But searching abstracts through PubMed is a great way to begin any search.

The At a Glance section provides some tips for determining how relevant the information is to the patient's search and clinical needs, starting with the study population and size. For example the confidence we can have in a study where $N = 16$ versus $N = 500$...

An understanding of basic statistical concepts will be needed to help judge the confidence we can have in clinical research findings, ... which is, of course, beyond the scope of this talk.



The PubMed registry, illustrated on slide 34, includes over 18 million citations from Medline and other sources.

Importantly, this registry is limited to published studies, and will not include media stories, advertisement, and so on.

And when you open an abstract, links to the full text and to related articles are also provided.



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
- Other
 - ASH.org (blood) | ASCO.org | Medscape.com

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Slide 35 is about quality treatment resource for cancers

Probably the first stop is to consult Cancer.gov and NCCN.org ..
... the websites of the National Cancer Institute and the National Cancer Care Network respectively.

Here you can find information regarding the Standard of Care for the specific cancer type and clinical settings.

Other outstanding, if technical resources, on treatment for cancers include ASH.org, Medscape.com, and ASCO.org

ClinicalTrials.gov is a publicly available database of investigational protocols for life-threatening diseases, which I'll cover on the next slide.

There is good news to report about this registry: new regulations (FDAAA 2007, section 801) requires sponsors of clinical trials to also publish the results to the same public registry. Martin Fenner, science reporter writes:

“This required reporting of results has so far largely gone unnoticed in the medical community, but will dramatically change the way research involving patients is conducted and reported. The 12 month deadline will probably lead to earlier reporting of many trial results, and not publishing negative results will be much more difficult. The required reporting in a standardized format will also facilitate the meta-analysis of several similar trials.”

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

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Moving to slide 36, Strategic Filtering: Investigational therapies may be considered, for example, when the standard of care is not curative, or when the cancer is refractory to available approved treatments. We may also consider participation in studies testing improvements in the standard of care.

ClinicalTrials.gov is a comprehensive and searchable registry of investigational interventions for cancers.

However, it can be daunting to locate studies that may be appropriate for a given diagnosis and clinical circumstance. Therefore, we encourage patients to also consult experts when considering clinical trials.

Note: Our group has proposed enhancements to the registry to help the main users (which happens to be patients and patient surrogates) to find studies based on our clinical circumstances – such as first line therapy, or post stem cell transplant.

The patient or physician might search further, beyond ClinicalTrials.gov using GOOGLE SITE SEARCH.

Note how the search begins with the command SITE, a colon, the site name, followed by the key words.

Site:www.cancer.gov drug name.

Use of online medical dictionaries will be needed also to help understand the technical language and basic medical terms. Very good dictionaries are provided on Cancer.gov. One example is shown.

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/

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More on Strategic Filtering.

As you may know, domain extensions provide clues about the website sponsor:

GOV stands for government, etc.

Nonprofits (ORGs) can be a great resource, particularly for survivorship topics

As discussed, Peer-based support is growing online, and so-called “open source” sites, such as Wikipedia.org, can provide in-depth information on an impressive and growing list of topics.

We advise caution for commercial sites, and to look out for Phishing (fishing) sites, that can look identical to reputable sites.

You can search also specific sites for support information using Google-based site-search, an example provided at the bottom of this slide.

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

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To slide 38 ... In summary:

= There are many unmet needs but also opportunities to care for the whole patient, including the use of online support services and information.

A news item from ASCO arrived only today in my inbox: Quote: “Oncologists increasingly consider the entire scope of life issues when designing treatment plans for patients. “... perhaps it's time to institute a checklist to make certain all aspects of care are covered.”

=Regarding what to trust, the common use of Alternative Medicine suggests that understanding of scientific method is lacking in the general public. We need to explain how clinical research is done -- and the standards and methods for that research -- to foster evidence-based-decision making.

= When consulting online medical resources about cancer and its treatments, patients need general guidance about where to look first, and how to distinguish between strong, weak, and implausible findings or claims.

Based on visitor questions and our website statistics (75 to 91 thousand unique visitors per month) it's evident that many patients and families are highly motivated and willing to help each other in this pursuit. The objective being to receive the best possible care and to become active partners in medical decision making.

= Finally, we introduced tips for searching and evaluating online medical information, utilizing PubMed, Cancer.gov, .org and .net and other resources.

Thanks for listening!

APPENDIX

Supplemental slides
& narrative
will be available:

www.Lymphomation.org/online-support.pdf